

Sex, Dementia, and Consent

by

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A thesis
presented to the University of Waterloo
in the fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Philosophy

Waterloo, Ontario, Canada, 2018

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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Abstract

Sex and dementia is becoming an increasingly important topic in applied ethics. By the year 2030, more than 74.7 million people are expected to be diagnosed with dementia worldwide; many of these people may want to engage in sex. The question of how to manage cases of sex and dementia is occurring more frequently in practical cases because of our aging population. The primary reason that sex and dementia is ethically complex is because sexual consent is both legally and morally significant, yet many people with dementia may be unable to consent in accordance with current standards.

In this dissertation, I introduce three frameworks that could be used to approach cases of sex and dementia. The first framework is that of relational autonomy and supported decision-making; this framework tries to enable people with dementia to make autonomous sexual decisions with support. The next approach is a framework of advance sexual consent, which considers the relevance of prior autonomous sexual decisions. The third framework focuses on prioritizing well-being above a person's capacity to make autonomous decisions and to consent to sex. I assess each framework and consider their positive and negative nuances. The overall goal is to balance the right to sexuality while at the same time protecting people with dementia from undue harm.

Ultimately, this dissertation shows that cases of sex and dementia ought to be managed on a case-by-case basis; one framework will not work for every context. In order to approach situations on a case-by-case basis, I contend that a process of weighing and balancing norms and principles is necessary. I use Beauchamp and Childress's method of weighing and balancing to propose a systematic procedure. This process takes various factors into account in order to determine how to proceed in an ethically defensible manner. According to an approach of

weighing and balancing, sexual acts would not be immediately barred based on a person's inability to consent; rather, a person's present convictions, the sexual activity to which they want to participate, the possibility of experiencing undue harm, their prior wishes and values, their capacity to make autonomous decisions with support, etc. would all be considered.

Overall, this dissertation contributes to the complex topic of sex and dementia and offers a starting point for further discussion on how to approach these cases in practice.

Acknowledgments

I am grateful to have been a doctoral student at the University of Waterloo. The Department of Philosophy has provided me with an enormous amount of support and I am incredibly thankful.

I would like to extend my sincerest appreciation to my supervisor, Dr. Patricia Marino. Her knowledge and expertise has been integral to the successful completion of this project. Since starting at Waterloo, Patricia has provided me with invaluable feedback, reassurance, and academic and professional guidance in the most caring and genuine manner. I am deeply grateful for her ongoing mentorship.

I would also like to acknowledge Dr. Shannon Dea and Dr. Mathieu Doucet for providing me with thoughtful and constructive feedback on my dissertation and for serving as academic mentors throughout my degree. Thank you to Dr. Sherry L. Dupuis for your inclusive work with the dementia population and for providing me with a new and practical perspective on my dissertation. Thank you to Dr. Elisabeth Gedge for your work in bioethics and for contributing your time and expertise to my project. I owe much thanks to Dr. Chris Lowry and Dr. Katy Fulfer for offering feedback on my work and advice about professional opportunities. I am grateful to Debbie, Angela, Tawnessa, and Vicki for helping me navigate the doctoral process. I would also like to thank my fellow philosophy students and friends. It was a pleasure to work and learn in such a collaborative and invigorating environment. I am especially thankful to my friends Jessica, Andrea, Yvonne, Catherine, Nikki, and Roz for their friendship and support. I want to extend a huge thanks to the UHN Bioethics team. It is an honour to work with such a thoughtful, generous, and inspiring group of people. I am grateful to Mr. Bubulj for introducing me to philosophy and to Dr. Davis and Dr. Behrendt for inspiring me to continue my studies in the field. Finally, I would like to acknowledge the Social Sciences and Humanities Research Council (SSHRC), the University of Waterloo, and the Department of Philosophy for providing me with financial support.

Finally, I want to extend the utmost thanks to my family. Thank you to my grandparents for cheering me on. I feel grateful to have you all in my life. Thank you so much to my parents, Michelle and Sam, and my brother, Anthony, for your ongoing love and support in all that I do. You have always encouraged me to do what makes me happy and supported me along the way. I would not have been able to achieve this milestone without you. Thank you to my life partner, Chris, for the very sincere love, support, patience, kindness, and guidance that you offered to me throughout this journey. Thank you for always believing in me and encouraging me to complete this goal. You inspire me everyday and I appreciate you more than words can describe.

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Introduction

By the year 2036, people who are sixty-five years of age and older will amount to approximately one quarter of Canada's population.¹ This has influenced scholars across disciplines to explore the implications of an aging population. In his book on the ethics of aging, Frits de Lange says that "[o]ur societies are being challenged economically and ethically as well. Intergenerational justice, social security, health-care access and distribution, filial responsibilities, the quality of life, and the human dignity of the oldest elderly— all these issues are in need of normative orientation and ethical reflection."² My dissertation responds to one area in need of critical ethical reflection that is seldom discussed—namely, the topic of sex and people with dementia. In 2016 there were an estimated 564,000 people diagnosed with dementia in Canada; sixty-five percent of those diagnosed were women. Only 16,000 people were under the age of sixty-five.³ Given that most people diagnosed with dementia are older than sixty-five years of age, this project fits into the growing branch of research on ethics and aging.⁴

There are approximately fifty million people living with dementia worldwide and this number is expected to increase to seventy-five million by the year 2030.⁵ According to

¹ Statistics Canada, "An aging population," October 7, 2016, accessed March 22, 2017, <http://statcan.gc.ca/pub/11-402-x/2010000/chap/pop/pop02-eng.htm>.

² Frits de Lange, *Loving Later Life: an ethics of aging* (Michigan: William B. Eerdmans Publishing Company, 2015), 3.

³ Larry W. Chambers, Christina Bancej, and Ian McDowell, eds., *Prevalence and Monetary Costs of Dementia in Canada: Population Health Expert Panel*, Alzheimer Society of Canada in collaboration with the Public Health Agency of Canada, 2016, http://alzheimer.ca/sites/default/files/files/national/statistics/prevalenceandcostsofdementia_en.pdf.

⁴ Alzheimer's Disease International, "Dementia Statistics," 2015, accessed March 22, 2017, <https://www.alz.co.uk/research/statistics>; this project is also relevant to people with dementia who are younger than sixty-five.

⁵ World Health Organization, "WHO launches Global Dementia Conservatory," 2018, accessed March 22, 2017, http://www.who.int/mental_health/neurology/dementia/en/; World Health Organization, "10 facts on Dementia," 2018, accessed January 21, 2018, <http://www.who.int/features/factfiles/dementia/en/>.

Alzheimer's Disease International, "someone in the world develops dementia every 3 seconds."⁶

Dementia is an umbrella term that is used to describe various brain disorders that cause a person's memory to decline, resulting in a reduced ability to perform daily functions and activities. The two brain disorders that are most likely to cause a dementia diagnosis are Alzheimer's disease and vascular dementia.⁷ Vascular dementia occurs after a stroke and Alzheimer's disease is when a person's brain cells stop functioning properly, causing other cells to "lose their ability to do their jobs and, eventually die, causing irreversible changes in the brain."⁸ Scientists are unaware of what causes Alzheimer's and there is currently no cure. The symptoms of a dementia diagnosis can vary depending on the individual and the underlying diagnosis, but some of the primary symptoms are: memory loss; language and communication challenges; lack of concentration; and impaired reasoning and judgment skills. This dissertation will be relevant to all people with dementia, but my focus will be on people with Alzheimer's disease since Alzheimer's is responsible for sixty-to-eighty percent of dementia diagnoses.⁹ Moreover, it represents most of the people discussed in the case studies in Chapter Two.

In the medical literature, dementia is described as a progressive disease and so a person's symptoms are expected to worsen over time. In the early stages of dementia, the most common symptoms are forgetfulness, some communication challenges, and changes in a person's mood/behavior. People in this stage will still be able to perform most daily activities and they

⁶ Alzheimer's Disease International, "Dementia Statistics."

⁷ Alzheimer's Association, "What Is Dementia?," 2018, accessed March 22, 2018, <https://www.alz.org/what-is-dementia.asp>.

⁸ Alzheimer's Association, "What Is Alzheimer's?," 2018, accessed March 22, 2018, https://www.alz.org/alzheimers_disease_what_is_alzheimers.asp.

⁹ Alzheimer's Association, "What Is Dementia?"

will have insight into their disease. In the mid-to-moderate stages, a person may experience increased memory loss, more challenges with language and communication skills, and they may require assistance with everyday tasks (e.g. homemaking, shopping, dressing, etc.). In the moderate-to-advanced stages of a dementia diagnosis, people will require significant support. They will eventually experience profound memory loss and become unable to communicate verbally.¹⁰ Another potential consequence for people in this stage, especially if they have frontal lobe dementia, is sexual disinhibitedness/sexual inappropriateness.¹¹ In the final months of dementia, people will have profound cognitive and physical decline. They will require continual support and nursing home placement is often necessary.¹²

In this dissertation I generally engage with the mainstream view that dementia is a progressive disease, but there are some other perspectives that consider dementia to be a different kind of experience. For instance, in their discussion of the troubling discourse that is used to describe dementia, Gail J. Mitchell, Sherry L. Dupuis, and Pia C. Kontos say that dementia is a “dynamic and fluid phenomenon that is not, as portrayed in the medical and societal discourses, a progressive, irreversible decline of one’s humanity.”¹³ The authors argue that the experiences of people with dementia regularly fluctuate, and so defining dementia as a progressive disease is misleading. This is an important perspective to consider since the

¹⁰ Alzheimer Society of Canada, “Stages of Alzheimer’s disease,” January 23, 2018, accessed March 22, 2018, <http://www.alzheimer.ca/en/Home/About-dementia/Alzheimer-s-disease/Stages-of-Alzheimer-s-disease#late-stage>.

¹¹ Loddon Mallee Regional Dementia Management Strategy, “Sexual Disinhibition: Preventing and managing sexual disinhibition or inappropriate sexual behaviour,” accessed May 15, 2017, http://dementiamanagementstrategy.com/Pages/ABC_of_behaviour_management/Management_strategies/Sexual_disinhibition.aspx.

¹² Alzheimer Society of Canada, “Stages of Alzheimer’s disease”; de Lange, *Loving Later Life*, 35; Maartje Schermer, “In search of ‘the good life’ for demented elderly,” *Medicine, Health Care and Philosophy* 6, (2003): 34-44, doi: 10.1023/A:1022571700463.

¹³ Gail J. Mitchell, Sherry L. Dupuis, and Pia C. Kontos, “Dementia Discourse: From Imposed Suffering to Knowing Other-Wise,” *Journal of Applied Hermeneutics* 5, (2013): 9.

symptoms of dementia are often described as fluctuating even from the viewpoint of healthcare professionals, however, healthcare workers will typically say that moments of lucidity for people with dementia will decrease over time *because* of the progressive nature of the disease. The primary aim of this dissertation should be of interest to people who hold either of these views. I do say that some of the symptoms of dementia may entail certain consequences when it comes to sex, and while I argue that some of the potentially detrimental consequences will typically be more relevant to individuals who are in the later stages of their disease, “the later stages” can be interpreted in terms of disease progression or in terms of a person who has less moments of lucidity/fluctuation of capacity. Ultimately, the difference of views will not be important in this dissertation.¹⁴

Given our aging population, improving dementia care has become a priority in Canada and in other parts of the world. In June 2017, Canada passed Bill C-233 which is “[a]n Act respecting a national strategy for Alzheimer’s disease and other dementias.”¹⁵ The strategy calls for all levels of government to enhance research efforts, improve access to care and support services, and assist provinces in developing standard clinical guidelines for treatment “so that

¹⁴ Furthermore, I do not subscribe to the view that dementia is or must be an irreversible decline of one’s humanity; my project is motivated by the idea that people with dementia are and ought to be sexual, which is arguably one of the most important aspects of humanity.

¹⁵ Parliament of Canada. *National Strategy for Alzheimer’s Disease and Other Dementias Act*. 1st sess., 42nd Parliament, June 22, 2017, Bill C-233, http://www.alzheimer.ca/sites/default/files/files/national/advocacy/c-233_4.pdf.

Canadians with dementia can have the best quality of life.”¹⁶ This call to action will complement some of the work already being done by existing organizations.¹⁷

Canada’s national dementia strategy encourages progress when it comes to managing society’s increased need for quality care. One topic in need of further consideration, however, is sex and dementia. Several cases involving sex and dementia have made news headlines in the recent past.¹⁸ While the specificities of these cases have differed, the pervasive conclusion has been that we, as a society, do not know how to manage situations when people with dementia engage in sexually intimate acts.¹⁹ This is a problem. In an interview discussing sex and dementia, reporter Bryan Gruley said that family members and nursing home staff are unprepared to handle cases of sex and dementia.²⁰ In another interview, Dr. Cheryl Phillips (an advocate for LeadingAge) said: “We’ll ask them [people with dementia] about their religion, the

¹⁶ Alzheimer Society of Canada, “Canada’s National Dementia Strategy,” November 8, 2017, accessed March 22, 2018, <http://www.alzheimer.ca/en/Home/Get-involved/Advocacy/National-dementia-strategy>; “Guide to the National Strategy for Alzheimer’s Disease and Other Dementias Act,” *Alzheimer’s Society of Canada*, November 8, 2017, <http://www.alzheimer.ca/en/Home/Get-involved/Advocacy/National-dementia-strategy/Alzheimers-Act>.

¹⁷ A few of the organizations trying to improve the quality of care and the treatment in society that people with dementia receive are: Dementia Friends Canada, accessed March 28, 2018, <http://www.dementiafriends.ca/>; Partnerships in Dementia Care (PiDC) Alliance, accessed March 28, 2018, <https://uwaterloo.ca/partnerships-in-dementia-care/>; Alzheimer Society of Canada, accessed March 28, 2018, <http://www.alzheimer.ca/en/Home>.

¹⁸ Pam Belluck, “Sex, Dementia and a Husband on Trial at Age 78,” *The New York Times*, April 13, 2015, <https://www.nytimes.com/2015/04/14/health/sex-dementia-and-a-husband-henry-rayhons-on-trial-at-age-78.html>; Melissa Block, “Can Elderly Patients With Dementia Consent To Sex?,” *National Public Radio, Inc.*, July 22, 2013, <https://www.npr.org/templates/story/story.php?storyId=204580868>; Philip Sherwell, “Judge lost husband to Alzheimer’s - and love,” *The Telegraph*, January 27, 2008, <https://www.telegraph.co.uk/news/uknews/1576716/Judge-lost-husband-to-Alzheimers-and-love.html>.

¹⁹ Kate Zernike, “Love in the time of dementia,” *The New York Times*, November 18, 2007, <http://www.nytimes.com/2007/11/18/weekinreview/18zernike.html>; Sherwell, “Judge lost husband to Alzheimer’s - and love”; Alyssa Gerace, “Senior Living Providers Seek Boundaries of Dementia and Sex,” *Senior Living News*, July 25, 2013, <https://seniorhousingnews.com/2013/07/25/senior-living-providers-seek-boundaries-of-dementia-and-sex/>.

²⁰ Block, “Can Elderly Patients With Dementia Consent To Sex?”

music they like, what kind of food they want to eat. We don't dream of asking them about their preferences around sexuality and intimacy"²¹—sex is a subject that is entirely ignored.

In *Sexuality, Disability, and the Law*, Michael Perlin and Alison Lynch consider whether the courts in the United States see sex as a fundamental right. In response, they say “the Supreme Court has never found sexual interaction per se to be a specifically protected right, and avoided the issue... [but] it has found a fundamental right to privacy in a broad array of cases involving reproductive choice.”²² Stephanie Tang makes a related remark in her discussion of sexual consent and elderly people with neurocognitive disorders. She says that “governmental and societal attitudes reflecting general discomfort with the idea of cognitively impaired elders engaging in sexual activity have resulted in an overall lack of laws, regulations, and general guidelines on the subject.”²³ A similar lack of rules and regulations exists in Canada. Because the act of having sex is not recognized as a fundamental legal right, it is the responsibility of family members, assisted living facilities, nursing homes, etc. to individually respond to any sexual acts that occur. However, many organizations (and probably many family members) “have difficulty dealing with intimacy and sex because [while] they are central to life satisfaction and psychological wellbeing, [they] are also constricted by moral values and cultural expectations.”²⁴ This poses a particular difficulty for vulnerable populations, such as some people with certain

²¹ Eliza Gray, “Why Nursing Homes Need to Have Sex Policies,” *Time Health*, April 23, 2015, <http://time.com/3833358/nursing-home-sex/>; LeadingAge is a non-profit organization whose mission is to help combat ageism. One of their strategic goals is to improve care for people with dementia.

²² Michael L. Perlin and Alison J. Lynch, *Sexuality, Disability, and the Law: Beyond the Law Frontier?* (New York: Palgrave Macmillan, 2016), 37.

²³ Stephanie L. Tang, “When Yes might Mean No: Standardizing State Criteria to Evaluate the Capacity to Consent to Sexual Activity for Elderly with Neurocognitive Disorders,” *Elder Law Journal* 22 (2015): 451.

²⁴ Perlin and Lynch, *Sexuality, Disability, and the Law: Beyond the Law Frontier?*, 79.

cognitive impairments and physical disabilities, who are dependent on others' approval and, perhaps, assistance, when it comes to engaging in sexual practices.

People with dementia are often regarded as non-sexual beings. There are at least two reasons that this view exists: (1) ageist stereotypes which suggest that older people are non-sexual and (2) the related conception that people with cognitive impairments are uninterested in sex. These conceptions may influence members of our society to assume that people with dementia are non-sexual as well. Beyond this descriptive claim (namely, the claim that people with dementia are non-sexual), however, it is also often thought that people with dementia *should not* engage in sexual acts because they may be unable to consent in traditional ways.²⁵ The idea is that if sexual consent is legally and morally important, and if people with dementia cannot consent in accordance with consent requirements, then they should not participate. Our aging population has been referred to as a “rape case timebomb”²⁶ because of concerns that people with dementia cannot consent and will, consequently, be victims of sexual assault.

If sexual consent is important and if people with dementia cannot consent in accordance with consent requirements, then we can proceed in either one of two ways: (1) accept that people with dementia cannot consent, and insofar as consent is legally and morally significant then people with dementia should not participate in sexual acts or (2) reconsider what sexual consent means for people with dementia and/or reevaluate the importance of consent for this demographic (i.e., consider whether our consent requirements need to change for this group).

The former option is how cases of sex and dementia are generally managed, namely, by stopping

²⁵ I will explain what it means to consent to sex in Chapter One. I will also explain why people with dementia may be unable to consent to sex in accordance with current frameworks.

²⁶ James Nye, “Sex and dementia: Aging population set for 'rape case timebomb' in nursing homes as Alzheimer rates rise,” July 23, 2013, *Daily Mail*, <http://www.dailymail.co.uk/news/article-2374771/Sex-dementia-Aging-population-set-rape-case-timebomb-nursing-homes-Alzheimer-rates-rise.html>.

the occurrence of sexual activities. This is illustrated in some of the cases discussed in Chapter Two. The problem with this response is that it does not respect the fact that people with dementia are sexual beings and that sexual acts can contribute to health and happiness; this conflicts with the other aims that our society promotes for people with dementia (e.g. enabling independence, health, and well-being).

In this dissertation, I initially consider some of the ethical complexities of sex and dementia. Subsequently, I introduce three frameworks that could be used to approach relevant cases. I ultimately find that different cases of sex and dementia ought to be managed differently. I suggest that a process of weighing and balancing conflicting norms and principles will be necessary to approach scenarios of sex and dementia on a case-by-case basis. I use Beauchamp and Childress's approach of weighing and balancing as a starting point to complete this task.

There are a surprising number of ways that the term "sex" can be defined.²⁷ Rather than referring to a specific definition in this dissertation (which has the potential to be too restrictive and heteronormative), I employ a broad conception of sex as an activity involving two or more people where the absence of consent would count as assault. If someone tries to kiss, penetrate (via penile penetration or using objects), or engage in oral sex with someone without their consent then it would be assault. I discuss some specific sexual activities throughout this dissertation that pose some particular complexities when it comes to consent and the potential for harm, such as BDSM (bondage, discipline, domination, submission, and sadomasochism). Ultimately, however, I adopt as a heuristic what would be considered sexual assault if consent were absent.

²⁷ Laurie J. Shrage and Robert Scott Stewart, *Philosophizing About Sex* (Toronto: Broadview Press, 2015), 4.

I consider consent to be an important part of sexual interactions. Consent ensures that all participating parties want to participate, thereby respecting their sexual autonomy and protecting them from undue harm. The purpose of this dissertation is *not* to argue against the importance of consent in and of itself. Rather, the purpose is to consider some of the ethical complexities of sex and consent when it comes to people with dementia since they may be unable to consent in accordance with traditional frameworks. I recognize that people with dementia are a vulnerable population who are more likely to experience sexual assault in comparison to other populations, yet I also realize that sex is an activity that people with dementia may find value in and want to pursue. Our cultural climate is changing to reflect an aging population and, as Stephen Schulhofer says, “law, and especially criminal law, never functions independently of the culture in which it is set.”²⁸ Our current sexual consent laws do not reflect some of the complexities and characteristics of our aging population who may be diagnosed with dementia. While the purpose of this dissertation is not to alter our legal system, it is possible that our legal structures may eventually change based on some of the considerations discussed.

In the first chapter of this dissertation, I explain why consent is legally and morally significant in Western liberal contexts. I describe familiar models of sexual consent and show why they may be unhelpful for people with dementia; many people with dementia, especially in the mid-to-moderate stages (and beyond) may be unable to consent to sex in accordance with traditional frameworks at most points in time.²⁹ I also discuss some intersectional challenges that may make consent particularly complex for some populations, such as women with dementia and

²⁸ Stephen J. Schulhofer, *Unwanted Sex: The Culture of Intimidation and the Failure of Law* (Massachusetts: Harvard University Press, 1998), 38-39.

²⁹ The reason that I specify that people with dementia may be unable to consent *at most points in time* is because all people with dementia can experience moments of lucidity. In their most lucid moments, it seems plausible that they may be able to consent.

LGBTQ2S³⁰ people. In the second chapter I outline some cases of sex and people with dementia. The cases that I introduce come from news reports, but there are likely many more similar cases that are unreported and unknown.³¹ Chapters Three, Four, and Five introduce three frameworks as possible ways to approach cases of sex and dementia. In Chapter Three, I introduce a framework of relational autonomy and supported decision-making. This framework considers what it would be like to enable autonomous sexual decision-making for people with dementia through a relational approach. Chapter Four considers a framework of advance sexual consent. In this chapter, I consider the possibility of seeing people with dementia as consenting to sex based on prior autonomous sexual decisions. This chapter draws on some medical literature regarding advance medical directives. Chapter Five introduces a framework of prioritizing well-being. The framework is based on the idea that prioritizing well-being through sex may be ethically defensible even if people with dementia cannot consent in typical ways. In order to determine whether a sexual activity may contribute to a person's well-being, I consider sexual desire, pleasure, and happiness as pertinent.

Sex is an important factor to consider when it comes to a person's health and well-being. However, sexual acts can cause unwanted physical and non-physical harm (e.g. being forced to engage in an unwanted act). In this dissertation, I show that people with dementia are sexual beings, yet I recognize that they may be more likely to experience certain types of harm in comparison to other groups. The vulnerability experienced by people with dementia is primarily based on their cognitive decline (which makes them susceptible to exploitation) and potential

³⁰ LGBTQ2S stands for: Lesbian, Gay, Bisexual, Trans/Transgender, Queer, Two-Spirit. This is the acronym that is currently used by "The 519" which is an organization in Toronto that offers support services, space, training, and leadership opportunities for the LGBTQ2S community. The acronym changes over time, and different acronyms get used in different communities. For the purposes of this dissertation, I will use the abbreviated version, LGBTQ, for the sake of readability.

³¹ Sherwell, "Judge lost husband to Alzheimer's - and love."

inability to consent to sex. The overall goal of the frameworks is to balance the right to sex and sexuality while at the same time protecting people with dementia from undue harm.

In Chapter Six, I discuss some of the positive and negative nuances of the three frameworks and propose a way to evaluate and approach cases of sex and dementia moving forward. Given the many complexities involved in sexual decision-making for people with dementia, I do *not* argue that one framework is better than the others for every context. Rather, I argue that the frameworks provide different principles and norms that ought to be considered for different kinds of cases (e.g. precedent autonomy, well-being, etc.). I suggest that Tom Beauchamp and James Childress's method of weighing and balancing conflicting bioethical principles can help to approach cases of sex and dementia on a case-by-case basis. Beauchamp and Childress's theory in bioethics is called "principlism".³² Principlism provides a foundation of bioethical principles that can be used to approach cases in bioethics. The four primary principles are: autonomy, beneficence, non-maleficence, and justice. Although specifying these principles on a case-by-case basis can be helpful, there may be some cases in which the principles conflict with one another, resulting in a moral dilemma.³³ In order to resolve moral dilemmas, Beauchamp and Childress say that a method of weighing and balancing conflicting values while at the same time taking into account the specificities of each case ought to be considered. In Chapter Six I explain this evaluation process for different kinds of cases of sex and dementia.

Ultimately, my thesis aims to consider some of the ethical complexities involved in cases of sex and dementia and explore the implications of different frameworks. I explain the challenges with well-known models of sexual consent and argue that we need to consider other

³² Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013), 25.

³³ Beauchamp and Childress, *Principles of Biomedical Ethics*, 11.

ways to approach future cases. The most appropriate framework to use when approaching cases of sex and dementia will differ depending on the factors involved in each case; this is why I propose a methodology of weighing and balancing. Overall, I hope that my dissertation encourages further conversations about sex and dementia so that our society can thoughtfully respond to the needs of this growing population.

Chapter 1

Background Considerations on Sexual Consent and Dementia

Before considering the frameworks that may be helpful to approach cases of sex and dementia, I will illustrate some challenging factors that make sex particularly complicated for this population. The reason that sex for people with dementia is so complex is mostly due to the significance that is placed on consent in Western liberal societies. However, some additional challenging factors are also important to consider when reflecting upon the topic of sex and consent more broadly.

In the first section of this chapter, I will explain the reasons that consent is legally important by providing a historical overview. I will also describe what is meant by sexual consent in Canadian law. Although the focus of this dissertation is to consider the ethics of sex, consent, and people with dementia, it is important to also recognize that there are pertinent legal implications (and that these legal implications are influenced by ethical values). Second, I will explain why consent is seen as morally significant, which mostly stems from the importance that is placed on autonomous decision-making. Explaining the moral significance of autonomous sexual consent helps to illustrate the primary ethical concern about sex and people with dementia, namely, that some people with dementia cannot engage in the kind of cognitive and communicative activities that we associate with autonomous consent. Third, I will consider the normative question of what sexual consent ought to involve by introducing familiar models of consent. The benefits and potential challenges of these models will also be described since it seems plausible that certain models of consent may be more appropriate for specific populations, such as people with dementia. After introducing these models of sexual consent, I will outline the importance of keeping certain intersectional challenges in mind throughout this dissertation.

By intersectional challenges I am referring to the challenges that may be experienced by people who identify as members of oppressed groups, which may influence their sexual experiences.

1- Sexual Consent as Legally Significant: A Historical Overview

There is a vast amount of literature regarding the history of sexual consent in the United States of America, most of which discusses rape law and the development of sexual consent policies.¹ The significance of sexual consent and the development of legal policies have been motivated in similar ways in Canada.² Sexual consent was not always seen as an important part of sexual acts, and while reforms have made consent more significant, there are still some problems that need to be resolved.

In the United States, the legal code did not originally recognize consent as a necessary requirement of engaging in sexual acts. Rather, the legal system used to determine whether sexual acts were legally permissible versus impermissible based on a man's sexual conduct as opposed to a woman's willingness to engage in sex.³ The law at this time was heteronormative, so much so that other laws at the time outlawed homosexual acts. Under this system, proof of physical force was required in order for a man to be charged with sexual assault. If a woman *did not* want to engage in sexual activities but eventually gave up her attempt of refusing to participate due to her partner's persistence, then she would be seen as consenting; other types of non-physical pressure (e.g. coercion) were seen as consistent with consent.⁴ In her analysis of

¹ Alan Wertheimer, *Consent to Sexual Relations* (New York: Cambridge University Press, 2003), 11.

² Elizabeth A Sheehy, "Introduction," in *Sexual Assault in Canada: Law, Legal Practice and Women's Activism*, ed. Elisabeth A Sheehy (Ottawa: University of Ottawa Press, 2012), 7.

³ Schulhofer, *Unwanted Sex*, 22.

⁴ Schulhofer, *Unwanted Sex*, 19; Susan Estrich, *Real Rape* (Massachusetts: Harvard University Press, 1987), 6.

rape law, Susan Estrich says that cases where a woman acquiesced to engage in unwanted sex without any extrinsic violence being imposed (e.g. guns, knives, beatings) were sometimes referred to as “simple rape” cases. The concept of a “simple rape” was compared to the concept of an “aggravated rape” (rape *with* extrinsic violence being imposed/threatened).⁵ If a woman submitted to engage in sexual acts with someone without proof of physical force then it was typically seen as consent. As stated by Schulhofer, consent was not something that necessarily implied actual desire under the law. Rather, “submission... *no matter how reluctantly yielded*, remove[d] from the act an essential element of the crime of rape.”⁶ So, if a woman submitted to sex because of coercion, abuses of trust, or undue pressure then a male would not be criminally convicted even if the woman dissented.⁷

Schulhofer gives an example that depicts how the forcefulness requirement was problematic. The example involves a woman who was riding her bicycle in an isolated area when she took a break. During this break she was approached by a stranger named Joel Warren. After conversing with Joel, the woman got on her bicycle and tried to leave, but Joel placed his hand on her shoulder and stopped her departure. The woman said “No, I have to go now” but he responded by saying “This will only take a minute. My girlfriend doesn’t meet my needs.” Joel then said “I don’t want to hurt you” which the young woman interpreted as a threat.⁸ Joel carried her into the woods, pulled off her pants, lifted her shirt to expose her breasts and forced her to perform several acts of oral sex. The woman did not scream or fight back because she was concerned that resisting would encourage Joel to physically harm her. After going to court,

⁵ Estrich, *Real Rape*, 4; Harry Kalven and Hans Zeisel, *The American Jury* (Boston: Little, Brown, 1966).

⁶ Schulhofer, *Unwanted Sex*, 19, italics in original.

⁷ Schulhofer, *Unwanted Sex*, 9-11, Estrich, *Real Rape*, 1987, 4-6.

⁸ Schulhofer, *Unwanted Sex*, 6.

prosecutors charged Joel with sexual assault. The court eventually overturned this conviction, however, noting that “the record is devoid of any attendant-circumstances which suggest that complainant was forced to submit.”⁹

Under the historical concept of sexual consent (just before the twentieth century), it was also entirely impossible for a husband to rape his wife.¹⁰ This was referred to as the marital rape exemption. Under the marital rape exemption, it was impossible for a husband to sexually assault his wife since a wife was expected to forfeit her legal existence to her husband.¹¹ As noted by legal scholar Rebecca Ryan, the relationship between a husband and wife was equivalent to that of a master and servant in the eighteenth century.¹² Adam Tuchinsky reinforces this position when he says that before the nineteenth century “married men and women were one person—effectively, the man.”¹³ Because a husband was responsible for his and his wife’s sexual activities, the possibility of a husband raping his wife was considered to be a paradox. If a husband wanted to engage in sexual acts then his wife was be legally required to abide by his request(s). One plausible reason that the husband assumed all of his wife’s rights was because of the patriarchal nature of the family. During this period in history, women were viewed as a dependency class and their survival was based on “the prosperity of those who feed them.”¹⁴ In

⁹ Schulhofer, *Unwanted Sex*, 1

¹⁰ Schulhofer, *Unwanted Sex*, 19; Rebecca M. Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” *Law & Social Inquiry* 20, no. 4 (1995): 944; Estrich, *Real Rape*, 37.

¹¹ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 944.

¹² Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 943.

¹³ Adam Tuchinsky, “Women and Her Needs”: Elizabeth Oakes Smith and the Divorce Question,” *Journal of Women’s History* 28, no. 1 (Spring 2016): 44.

¹⁴ Kate Millett, *Sexual Politics* (New York: Columbia University Press, 1970), 38.

this context, marital sex was always seen as consensual since a married woman was perceived to have consented to all subsequent sexual (and non-sexual) activities upon being married.¹⁵

In the nineteenth century the concept of a “right-less” wife started to encounter significant criticism.¹⁶ This criticism was introduced as part of the women’s rights movement, where advocates fought for freedom through “a world of self-ownership, contract, and consent.”¹⁷ In response to this movement to fight for women’s freedom and independence in marital contexts, legislators granted married women greater economic independence. However, they did not alter the wife’s role by broadening her sexual rights; the husband still “owned a natural sexual authority.”¹⁸

The concept of a “right-less” wife continued to be criticized in the twentieth century by feminist and battered women’s movements who said that marriage ought to be based on equality, not hierarchy.¹⁹ In 1971, the United States Supreme Court responded to this movement in their decision of *Eisenstadt v. Baird*, which allowed for equal access to contraceptives both in and outside of marriage.²⁰ This was a substantial legal milestone since, prior to this point, a married woman was considered to be part of a unit that transcended her status as an individual. In *Eisenstadt v. Baird*, the court recognized that only granting certain privileges to married individuals (by only allowing married couples to access contraceptives) violated the Equal

¹⁵ Wertheimer, *Consent to Sexual Relations*, 12.

¹⁶ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 945.

¹⁷ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 945; Tuchinsky, “Women and Her Needs”: Elizabeth Oakes Smith and the Divorce Question,” 45.

¹⁸ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 947.

¹⁹ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 969.

²⁰ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 972.

Protection Clause of the Fourteenth Amendment.²¹ The decision to grant married and unmarried people the right to access contraceptives was significant in defeating the marital rape exemption since “the court denied the basis for any specific marital privileges in the law”²² which was previously used to justify the exemption.

The New York court used the *Einsenstad v. Baird* ruling to support their 1984 decision in *People v. Liberta*, where they convicted a man for raping his wife. This set a precedent to abolish the marital rape exemption. The reason that a husband could no longer be exempted from raping his wife was because, after the decision in *Einsenstad v. Baird*, it was considered unlawful to grant unique privileges to married individuals. The *Einsenstad v. Baird* case reinforced the idea that marital unity did not transcend people’s individual rights, thereby granting women the right to be treated as separate individuals from their husbands in both sexual and non-sexual contexts. In the case of *People v. Liberta*, Judge Wachtler said that failing to grant a married woman any rights over her body was outdated in a 1984 courtroom. So, as a consequence of the feminist movement and the *Einsenstad v. Baird* ruling, the marital rape exemption was overturned.²³ Similar to the United States, Canada’s sexual assault laws changed in the early 1980s as a result of women’s activism and feminist thought.²⁴

When the marital rape exemption was abolished, consent became an important part of engaging in sexual acts so that people could avoid being charged with rape. Since both married and unmarried persons were independent legal entities, they were given the right to consent or

²¹ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 972.

²² Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 972.

²³ Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 989 and 973.

²⁴ Sheehy, “Introduction,” 7.

refuse to consent to sex.²⁵ At this point in time, the concept of autonomous decision-making became pertinent to evaluating the legal permissibility of sex. From this new perspective of men's and women's rights, a person's autonomous decision to engage or to not engage in sex deserved respect both in and outside of marital contexts.

Sexual consent continues to be an important part of engaging in legal sex in Western liberal societies. However, there are several consistent definitions and conceptions of what consent entails and what ought to be classified as sexual assault and rape. In her discussion of feminist conceptions of rape, Ann Cahill poses some questions that are frequently asked about how to define rape: "what exactly is wrong in the wrong of rape? The application of force? The lack of consent? ... How are we to understand what rape does and can do to women?"²⁶ There is not one agreed upon definition. An example of this variation can be seen in the United States, where legal rape statutes vary by state; some states define rape only as sexual intercourse without consent, and some include anal sex and foreign-object penetration. Until 2013, many states would convict a person of rape only if they used or threatened to use physical force on their victim.²⁷ In 2013, the Uniform Crime Reporting (UCR) Program of the Federal Bureau of Investigation (FBI) altered their definition of rape to: "Penetration, no matter how slight, of the vagina or anus with any body part or object, or oral penetration by a sex organ of another person,

²⁵ Ryan, "The Sex Right: A Legal History of the Marital Rape Exemption," 993; Wertheimer, *Consent to Sexual Relations*, 17.

²⁶ Ann J. Cahill, *Rethinking Rape* (New York: Cornell University Press, 2001), 2.

²⁷ Wertheimer, *Consent to Sexual Relations*, 16 and 17; Samantha Cowan, "See How Your State Legally Defines Rape (or Doesn't)," *TakePart*, June 29, 2016, <http://www.takepart.com/article/2016/06/29/state-rape-laws>.

without the consent of the victim.”²⁸ However, not all states adhere to this definition and some do not legally define rape but rather classify all forms of sexual penetration as separate crimes.

In Canada, there is one dominant Criminal Code that guides all criminal activities across the nation, distinguishing it from the state-based criminal system in the United States of America. According to Section 273.1 of Canada’s Criminal Code, all participating parties involved in a sexual interaction must voluntarily consent to sex in order for either party to avoid committing a legal offense.²⁹ Under this legal framework, consent must be explicitly communicated – implied consent does not exist.³⁰ Explicit consent can be expressed verbally or non-verbally and a person must continue to consent during the sexual activity.³¹ A person who is unduly influenced to participate in sexual acts and/or does not provide verbal or non-verbal consent can be a victim of sexual assault even if there are no physical ramifications. The law supports the view that originated in the women’s movement, whereby all people ought to have an equal right to choose to engage in sexual acts and to be protected from undue physical or psychological pressures to unwillingly participate.³²

While the Canadian legal system outlines conditions about what it means to engage in lawful sex, one potential criticism is that it may not respond to some of the complex nuances that

²⁸ U.S. Department of Justice, “An Updated Definition of Rape,” January 6, 2012, accessed March 21, 2018, <https://www.justice.gov/archives/ovw/blog/updated-definition-rape>.

²⁹ Government of Canada- Department of Justice, *A Definition of Consent to Sexual Activity*, January 7, 2015, accessed March 29, 2018, <http://www.justice.gc.ca/eng/cj-jp/victims-victimes/def.html>.

³⁰ Sarah Boesveld, “Canadian law decisive on what constitutes sexual consent: there's nothing 'implied' or 'implicit' about it,” *National Post*, November 26, 2014, accessed March 22, 2018, <http://nationalpost.com/news/canada/canadian-law-decisive-on-what-constitutes-sexual-consent-theres-nothing-implied-or-implicit-about-it>.

³¹ Government of Canada, *A Definition of Consent to Sexual Activity*; “Only 1 in 3 Canadians Know What Sexual Consent Means,” (Canadian Women’s Foundation, May 5, 2015, accessed January 21, 2018, <https://www.canadianwomen.org/about-us/media/1-3-canadians-know-sexual-consent-means/>).

³² Ryan, “The Sex Right: A Legal History of the Marital Rape Exemption,” 969.

are involved in sexual acts. For instance, the law does not provide specific guidance on how people can accurately express and interpret verbal and non-verbal consent. In order to clarify what consent is and/or what it ought to entail, various models of sexual consent have been proposed in recent years. Some of these models may be more helpful in certain contexts and for particular people, such as, perhaps, persons with dementia. These models of sexual consent will be considered later in this chapter and referred to at times during this dissertation.

2- Sexual Consent as Morally Significant: A Historical Overview

Sexual consent is also morally important. In their discussion on the ethics of sexual consent, Laurie Shrage and Robert Scott Stewart say that consent is a minimum requirement of moral decency in sexual acts.³³ Similarly, in his book on sexual consent, David Archard says that “consent makes a difference to whether some sexual activity is seen as immoral or not.”³⁴ The sexual activities that occur between consenting adults are typically seen as morally permissible “even if the rest of us find a particular practice disgusting or shocking.”³⁵ Archard says that some people consider consent to be “morally transformative” since “it can suddenly make an otherwise wrong action right.”³⁶ According to Archard, the general view of consent and morality consists of two principles, namely, the principle of consensuality and the principle of non-consensuality. He describes the principles in the following way:

³³ Shrage and Stewart, *Philosophizing about Sex*, 36.

³⁴ Archard, *Sexual Consent*, 1.

³⁵ Archard, *Sexual Consent*, 1.

³⁶ Archard, *Sexual Consent*, 3; Heidi M. Hurd also says that consent is a type of “moral magic” (Heidi M. Hurd, “The Moral Magic of Consent,” *Legal Theory* 2, (1996): 121-146).

The Principle of Consensuality states that ‘a practice, P, is morally permissible if all those who are parties to P are competent to consent, give their valid consent, and the interests of no other parties are significantly harmed’. The Principle of Non-Consensuality states that ‘a practice, P, is morally impermissible if at least one of those who are parties to P, and who are competent to consent, does not give their valid consent, even if the interests of no other parties are significantly harmed’.³⁷

Drawing from Archard, one of reasons that consent is morally important is because consent protects people, specifically women, from the harms that may result from engaging in unwanted sex due to paternalistic norms.³⁸ As mentioned above, mutual sexual consent was historically unimportant since women were dominated by patriarchal laws that prioritized men’s desires. These paternalistic norms harmed women by failing to recognize them as independent people with interests; consent was proposed as a way to avoid and prevent this kind of harm. Some theorists suggest that having non-consensual sex can cause a specific type of harm due to the deeply intimate nature of sexual activities that is different than other acts.³⁹ For instance, Archard says that people who engage in sex inevitably expose themselves to certain vulnerabilities that can affect their self-esteem and self-confidence. He says that sex is “carnal, and as incarnated beings we have a very strong interest and regulating and controlling access to our bodies.”⁴⁰ Sexual consent is morally important since it can reduce the potential for undue harm by ensuring that people want to participate in a deeply intimate activity.

³⁷ Archard, *Sexual Consent*, 2.

³⁸ While the purpose of establishing rules of consent was based on women’s experiences, it is also true that men, boys, girls, and nonbinary people are subject to violence.

³⁹ Archard, *Sexual Consent*, 20; Cahill, *Rethinking Rape*.

⁴⁰ Archard, *Sexual Consent*, 20.

Another widely agreed upon reason that sexual consent is morally important is because of the significance that is placed on autonomy in Western liberal societies.⁴¹ The principle of autonomy is often referred to in bioethics, where it is thought people deserve the right to make their own informed decisions even if others judge their decision(s) to be harmful or wrong.

Stephen Schulhofer describes sexual consent as an act that can be used to measure a person's sexual autonomy. He defines sexual autonomy as "the freedom of every person to decide whether and when to engage in sexual relations."⁴² So, instead of determining whether a woman was assaulted based on her partner's acts, Schulhofer says that we should focus on whether a woman positively and autonomously chose to participate. Similarly, Archard says that one of the reasons that consensual sex is typically considered to be morally permissible is because of the idea that "individuals should be free to do as they choose."⁴³

Lastly, sexual consent may be seen as morally significant from a Kantian perspective. This perspective is also discussed (though not endorsed) by Archard in his discussion of sexual consent and in Cahill's discussion of rape.⁴⁴ According to Kant's moral philosophy, a person must always treat others as ends in themselves and never as a mere means.⁴⁵ A person who engages in sex for their own purposes without obtaining consent from their partner may be accused of treating their partner as a mere means, which is always (according to Kant) morally

⁴¹ Beauchamp and Childress, *Principles of Biomedical Ethics*.

⁴² Schulhofer *Unwanted Sex*, 99.

⁴³ Archard, *Sexual Consent*, 40.

⁴⁴ Archard, *Sexual Consent*, 40; Cahill, *Rethinking Rape*, 181.

⁴⁵ Immanuel Kant, 1724-1804. *Groundwork of the Metaphysics of Morals*. Ed. Mary J. Gregor and Jens Timmermann (Cambridge: Cambridge University Press, 2012).

wrong. Consensual sex ensures that all participating parties respect their partners' autonomous sexual interests and treat them as ends in themselves.

3- The Workings of Sexual Consent

As stated in the Introduction, sex is a moralized and taboo topic, encouraging a wide range of potentially conflicting perspectives. Because there are many views about sex, it is possible that sexual partners may have conflicting sexual expectations and desires, making it difficult to know whether a person wants to have sex unless they communicate their consent in a clear and explicit way (and even then, it can be hard to be certain).

The importance of obtaining clear consent has gained increasing attention in recent years, as influenced by the feminist movement and growing respect for autonomy in the sexual domain. Different models of sexual consent have been proposed as a response to the normative question of how people ought to express their willingness and/or unwillingness to participate in sex, such as “no’ no means no” and affirmative consent models. Each of these models was proposed in response to some of the feminist critiques raised against paternalistic sexual norms, and so they are framed with a specific goal to address the potential vulnerabilities of women. These models of consent take into account some of the complexities of sexual acts, some of which may be pertinent to people with dementia. It is important to note, however, that proponents of the “no’ no means no” and affirmative consent models do not think about their models as being helpful for only specific types of people. Rather, they think that their models are applicable to, and right under, all circumstances.

(1) “‘No’ means no”:

The “‘no’ means no” model of sexual consent was developed to protect women from sexually abusive and/or unwanted sexual experiences. It was a response to the forcefulness requirement in the law, which, as discussed above, suggested that a woman who acquiesced to sexual acts even after being influenced by physical pressure may be seen as consenting.

Proponents of the “‘no’ means no” model aim to defeat this conception about force by clarifying that a woman’s “no” actually means “no”. In her book *Real Rape*, Estrich says that a man who believes that a woman wants to participate sexual acts when she says “no” is unreasonable.⁴⁶ And insofar as a *reasonable* belief about a woman’s consent is required in order for a man to *not* be charged with sexual assault, then a man who believes that a woman consented even when she said “no” ought to be punished under the law. According to Estrich, “[c]onsent” should be defined so that no means no.⁴⁷ Estrich’s reason for supporting a “‘no’ means no approach” is because “many women who say yes to men... would say no if they could. [There is] no doubt that women’s silence sometimes is the product not of passion and desire but of pleasure and fear. Yet if yes may often mean no, at least from a woman’s perspective, it does not seem so much to ask men, and the law, to respect the courage of the woman who does say no and to take her at her word.”⁴⁸

The “‘no’ means no” model of sexual consent helps to protect women’s rights to make their own sexual decisions by clarifying that a woman’s “no” ought to be taken seriously. However, the model has received some pushback. The most prevalent problem communicated about the “‘no’ means no” model is that some women may be unwilling or unable to verbally say

⁴⁶ Estrich, *Real Rape*, 98.

⁴⁷ Estrich, *Real Rape*, 102.

⁴⁸ Estrich, *Real Rape*, 102.

“no” if they are frozen in fear due to implicit or explicit physical or non-physical threats, power imbalances, and/or social pressures to comply with sexual requests.⁴⁹ Critics of the “‘no’ means no” model suggest that a woman who does not explicitly dissent may not be consenting even though this is the presumption.⁵⁰ The model does not consider the possibility that silence and/or acquiescence may be quite rational for a woman who feels/is being threatened with violence.⁵¹

Schulhofer provides some non-sexual examples to show why the “‘no’ means no” model of consent may be problematic in the sexual domain and why consent should involve some positive act. One of the examples considers the relationship between a doctor and patient. Schulhofer says that if a doctor asks their patient whether they consent to having a probe inserted into their rectum to check for tumors and the patient remains silent, then consent would not be presumed. A person who does not say “no” does not necessarily want to participate. In a medical context, informed consent is a necessary part of the consent process, and a positive expression of consent needs to be given. Schulhofer says that even in contexts when informed consent is not legally required, “many situations still require actual permission, not just silence.”⁵²

Schulhofer also says that what happens after the “no” is a problem that needs to be considered for sexual interactions. In some circumstances, women who say “no” actually do mean “yes” because they have been socialized to do so, as shown in Charlene Muehlenhard’s and Lisa Hollabaugh’s 1988 report. Muehlenhard and Hollabaugh performed a study on 610 college women at Texas A&M University, where 39.9% of the women surveyed said that they

⁴⁹ Pamela Haag, *Consent: Sexual Rights and the Transformation of American Liberalism* (New York: Cornell University, 1999), xvii; Shrage and Stewart, *Philosophizing about Sex*, 35.

⁵⁰ Michelle J. Anderson, “Negotiating Sex,” *Southern California Law Review* 78, (2005): 1404.

⁵¹ Estrich, *Real Rape*, 58.

⁵² Schulhofer, *Unwanted Sex*, 270.

had offered “token resistance” to sex “even though [they] had every intention to and [were] willing to engage in sexual intercourse.”⁵³ This is likely because they had been taught or socialized to do so and/or or they did not want to seem too “easy”.⁵⁴ Carol Pateman also discusses the notion of token resistance. Pateman considers Rousseau’s interpretation of gender roles in sex, where men are seen as “natural” aggressors and women are seen as “destined to resist”; women are socialized to ‘always say “no” [to sex] even when they desire to say “yes.”’⁵⁵ This poses a problem with the “‘no’ means no model” because “no” does not, in fact, always mean “no”. If a woman is socialized to say “no” even when she means “yes”, then the “‘no’ means no” model is not a reliable method of gauging whether a woman wants to participate; this directly contrasts with Estrich’s claim above.

The first criticism of the “‘no’ means no” model may be especially important to consider when it comes to people with dementia. Considering that many people with dementia may be unable to effectively communicate their sexual preferences due to some of the symptoms of their dementia (e.g. language and communication difficulties), any model that requires someone to refuse to consent to sex in an explicit way (to say “no”) may be challenging.

(2) Affirmative Consent:

Affirmative consent models were proposed as a response to some of the challenges of the “‘no’ means no” model. Affirmative consent requires individuals to express their voluntary and affirmative agreement to participate in sexual acts as a way of consenting.

⁵³ Charlene L. Muehlenhard and Lisa C. Hollabaugh, "Do Women Sometimes Say No When They Mean Yes? The Prevalence and Correlates of Token Resistance to Sex," *Journal of Personality and Social Psychology* 54, no. 5 (1988): 872.

⁵⁴ Muehlenhard and Hollabaugh, "Do Women Sometimes Say No When They Mean Yes? The Prevalence and Correlates of Token Resistance to Sex," 878.

⁵⁵ Carol Pateman, “Women and Consent,” *Political Theory* 8, no. 2 (1980): 154.

Affirmative consent models are sometimes referred to as “‘yes’ means yes” models of sexual consent. The idea is that a person who does not communicate “yes” to sex cannot be interpreted as consenting. According to affirmative consent models, the onus is on sexual partners to explain why they believed that a person agreed to pursue sexual acts with them during a sexual assault investigation. As noted by Lisa Maatz, Vice President of government relations at the American Association of University Women, affirmative consent policies dissuade people involved in disciplinary proceedings to ask sexual assault victims stigmatizing and insinuating questions such as “‘Did you fight back?’ or ‘Have you had a relationship with the accused?’ or ‘What were you wearing?’”⁵⁶ Affirmative consent policies provide protection to all people in heterosexual and homosexual relationships, though most theorists who examine these policies focus on women engaging in heterosexual sex given the higher rates of sexual assault and the likelihood of being misinterpreted when it comes to remaining silent, acquiescing due to socialization norms, etc.

One of the first formal sexual consent policies that required affirmative consent was the sexual offense policy of Antioch College.⁵⁷ Some of the main components of the policy were: sex must be consented to verbally before contact; attaining consent is an ongoing process throughout a sexual encounter; people need to express consent when the level of intimacy increases; a request for consent must be specific to each act; if someone stops consenting then they should communicate verbal withdrawal; do not ever make assumptions about consent, etc.⁵⁸

⁵⁶ Tyler Kingkade, “Colleges Are Rewriting What Consent Means To Address Sexual Assault,” *Huffington Post*, September 11, 2014, http://www.huffingtonpost.ca/entry/college-consent-sexual-assault_n_5748218.

⁵⁷ Alan Soble, “Antioch's "Sexual Offense Policy": A Philosophical Exploration,” *Journal of Social Philosophy* 28, no. 1 (1997): 22-36; Patricia Marino, “Philosophy of Sex,” *Philosophy Compass* 9, no. 1 (2014): 22-32, doi: 10.1111/phc3.12098.

⁵⁸ Soble, “Antioch's "Sexual Offense Policy": A Philosophical Exploration,” 25.

The Antioch Policy did not make any exceptions for people who had previous sexual encounters; a person needed to affirmatively consent to each sexual act on each sexual occasion.

Furthermore, one could not consent to a whole night of sexual acts or to any future acts.

Although Antioch College's affirmative consent policy was originally drafted in 1991, an increased number of affirmative consent policies have been developed in recent years.⁵⁹ One of the most prominent examples of the increased implementation of affirmative consent policies occurred in 2014 when the state of California legally mandated all universities receiving state funds to incorporate affirmative consent standards within their sexual violence and sexual education systems. Shortly thereafter, it was confirmed that over 800 universities in the United States implemented some form of affirmative consent standard.⁶⁰ It is important to note that most of these policies allow for some form of non-verbal consent.

Two specific models of affirmative consent have been proposed to promote a more accurate interpretation of what affirmative consent should look like in practice. I will refer to the first model as Communicative Sexuality and the second model as the Negotiation Model. Each of these models provide specific outlines of what is meant by affirmative consent that go beyond the standard description of "'yes' means yes".

Communicative Sexuality:

In her article, "Date Rape: A Feminist Analysis" Lois Pineau proposes a model of affirmative consent, which she refers to as communicative sexuality. Pineau's model is

⁵⁹ Nick Anderson, "Sex offense statistics show U.S. college reports are rising," *Washington Post*, July 1, 2014, https://www.washingtonpost.com/local/education/sex-offense-statistics-show-us-college-reports-are-rising/2014/07/01/982ecf32-0137-11e4-b8ff-89afd3fad6bd_story.html?utm_term=.b850efbab944; "Sex offenses on U.S. college campuses" *Washington Post*, 2012, <http://apps.washingtonpost.com/g/page/local/sex-offenses-on-us-college-campuses/1077/>; Timothy Sawa and Lori Ward, "Sex assault reporting on Canadian campuses worryingly low, say experts," *CBC News*, February 6, 2015, <http://www.cbc.ca/news/canada/sex-assault-reporting-on-canadian-campuses-worryingly-low-say-experts-1.2948321>.

⁶⁰ Kingkade, "Colleges Are Rewriting What Consent Means To Address Sexual Assault."

specifically meant to help mitigate date rape occurrences. She considers what consent should look like based on what is reasonable from a woman's point of view.⁶¹ Pineau's focus on heterosexual relations and her decision to specifically present a woman's point of view may reflect the time in which her article was published, which was 1988.

Communicative sexuality requires all participants to ensure that their partner(s) wants to continue a sexual interaction.⁶² Pineau says that if a man wants to be certain that he is not forcing himself on a woman then he must ensure that the sex is mutually enjoyable and/or be aware of why a woman would want to have sex in spite of her enjoyment. An example of why a woman might want to have sex despite her enjoyment might be because she cares about pleasing her partner. However, Pineau says that we should *not* assume that it is "reasonable for women to consent to what they have little chance of enjoying"⁶³ such as aggressive sex.

Pineau suggests that sexual preferences ought to be communicated both in advance of and during a sexual encounter, extending beyond a mere "yes". Evidence of an ongoing positive response from both partners is needed; both verbal and non-verbal cues are acceptable insofar as they have been communicated and agreed upon in advance. In response to the fact that women are more likely than men to be sexually abused, Pineau's proposal blames date rape occurrences on men's failure to approach sex in a communicative way and to make unreasonable assumptions about potential sexual advances (e.g. a woman who is dressed provocatively). She argues that reckless indifference and/or willful ignorance on the part of the man would be considered sexual assault.⁶⁴

⁶¹ Lois Pineau, "Date rape: A feminist analysis," *Law and Philosophy* 8, no. 2 (1989): 217-243.

⁶² Lois Pineau, "Date rape: A feminist analysis," 221.

⁶³ Pineau, "Date rape: A feminist analysis," 239.

⁶⁴ Pineau, "Date rape: A feminist analysis," 240.

Negotiation model:

Michelle Anderson's "Negotiation Model" is similar to Pineau's. This model requires partners to negotiate acts of sexual penetration through reciprocal communication. The model does not assume heterosexuality and it is gender-neutral.⁶⁵ One of the primary differences between Anderson's proposal and other models of sexual consent, such as Pineau's, is that Anderson's only applies to acts of sexual penetration. She does not require people to negotiate "each potentially romantic act."⁶⁶ Similar to Pineau, however, Anderson says that while verbal communication is preferable, sexual partners can communicate non-verbally as long as they establish a way to accurately gauge non-verbal behaviour prior to a sexual occurrence.⁶⁷ This allowance for non-verbal consent responds to the potentially unrealistic expectation that long-time consensual sexual partners will verbally and explicitly say "yes" every time they want to participate in sexual acts. Anderson's model asks, "Did the person who initiated sexual penetration negotiate with his or her partner and thereby come to an agreement that sexual penetration should occur?"⁶⁸, placing the onus on both the initiator and their partner to discuss their sexual interests, preferences, and, most importantly, the method(s) of communication that they would use during sex.

⁶⁵ Anderson, "Negotiating Sex," 1424.

⁶⁶ Anderson, "Negotiating Sex," 1422.

⁶⁷ Anderson, "Negotiating Sex," 1421.

⁶⁸ Anderson, "Negotiating Sex," 1423.

4- *Critiques of Communicative Sexuality and Negotiated Consent*

One of the most widespread criticisms against Pineau's and Anderson's models of affirmative sexual consent is that they are too formal and unrealistic. Stephen Schulhofer says that requiring ongoing affirmative consent as well as previously agreed upon non-verbal cues "impos[es] a degree of formality and artificiality on human interactions in which spontaneity is especially important."⁶⁹ A similar criticism is raised by David Archard, specifically when it comes to committed intimate partners. Archard says:

It seems absurd to require of an intimate, loving couple that in every one of their sexual encounters they should seek the explicit consent of one another, either's failure to do so being culpable since the absence of explicit consent shall count as non-consent. The absurdity lies in the extension to one type of relationship—characterised by love, long familiarity, mutual understanding, and trust—of presumptive standards which are certainly appropriate to another type, that, for instance, between strangers.⁷⁰

In response to this kind of criticism, however, Anderson says that the reality "is that AIDS killed the romance of uncommunicative sex twenty years ago"⁷¹ and negotiated communication in sex is necessary in order to protect people from experiencing undue consequences (such as sexually transmitted diseases). An additional response may be that communicative consent outweighs any potential loss of romance/spontaneity because of the importance of respecting individuals' autonomous sexual decisions (which may change throughout the course of a relationship).⁷²

⁶⁹ Schulhofer, *Unwanted Sex*, 272; Anderson, "Negotiating Sex," 1437; Verbal communication is preferable, though not required, on both Pineau's and Anderson's accounts.

⁷⁰ Archard, *Sexual Consent*, 146.

⁷¹ Anderson, *Sexual Consent*, 1437.

⁷² One may also respond by simply saying that communicative consent does not result in a loss of romance and Archard's position is just false.

Moreover, it seems that enabling and respecting individuals' autonomous sexual decisions may be especially important to consider for certain populations.

For the purposes of this dissertation, I am most interested in considering the specific characteristics of people with dementia and why dementia may pose a problem when it comes to certain interpretations of sexual consent. While Schulhofer's criticism of affirmative consent models is that they are too demanding to allow for spontaneous sexual interactions to occur, he fails to consider the possibility that these models may be suitable for people to whom spontaneous sexual interactions could pose some serious challenges. Given that people with dementia often experience language and communication challenges, and since their ability to make decisions sometimes requires additional support, it is almost certain that many people with dementia would not be accurately interpreted and/or able to make informed choices *without* something like a communication or negotiation model. While this may not justify entirely dismissing the possible benefits and/or appeal of sexual spontaneity, it is at least something that ought to be considered upon contemplating different models of consent for different populations.

Another criticism of affirmative consent models is the reliability of a woman's "yes" and the efficacy of affirmative consent when it comes to protecting women from undue harm. In her discussion of consent, Pateman poses the following question: "if "no," when uttered by a woman, is to be reinterpreted as "yes," then... [w]hy should a woman's "yes" be more privileged, be any the less open to invalidation, than her "no"?"⁷³ In response to this rhetorical question, Pateman says that there can be no answer "until women are admitted unequivocally as

⁷³ Pateman, "Women and Consent," 162.

“free and equal individuals.”⁷⁴ Pateman’s criticism of affirmative consent is relevant to any model of consent since her main concern is the social structure under which these models exist.⁷⁵

I want to conclude this section with some brief remarks on the applicability of the models we have seen for people with dementia. The “‘no’ means no” and affirmative models of sexual consent are meant to be pertinent to all people. However, these models may be generally unhelpful when it comes to consent and people with dementia. The reason that these models may be unhelpful is because many persons with dementia may be unable to consent to sex in accordance with these frameworks, especially as their disease progresses. These frameworks require individuals to have the capacity to consent to sex in a certain kind of way, and as Archard says, for some individuals the “lack of such a capacity [to consent] may be permanent, as would be the case with someone who is seriously mentally ill or disabled [such as someone with dementia].”⁷⁶ The reason that a person with dementia might be unable to consent in accordance with these frameworks is because of certain symptoms that are associated with a dementia diagnosis, such as a lack of understanding, impaired judgment, language or communication challenges, and/or an inability to fully understand the activity to which they are consenting.⁷⁷ Moreover, people with dementia are often seen as non-autonomous (which will be further discussed in the next chapter), which poses an evident problem if autonomous sexual decisions are an essential part of these frameworks.

⁷⁴ Pateman, “Women and Consent,” 162.

⁷⁵ Archard, *Sexual Consent*, 87; Archard discusses Pateman’s views of consent in light of gender inequality.

⁷⁶ Archard, *Sexual Consent*, 44.

⁷⁷ Similarly, they might be unable to recognize when their sexual partner(s) provides legitimate consent.

5- *An Additional Challenge*

One factor that I aim to keep in mind throughout this dissertation is that of intersectional challenges for people with dementia and how these challenges may be pertinent when it comes to sex and consent. The stigmatizing perspectives around who ought to engage in sex accords with what Gayle Rubin refers to as *hierarchical sex acts*, which is the idea that sexual acts are ranked according to their sexual value in Western societies. Sex is considered to be the most appropriate when it occurs between heterosexual married people, followed by unmarried monogamous heterosexual couples.⁷⁸ The types of sexual acts that are lower on the hierarchy are homosexuality and having sex with more than one person. The intersectional challenges that people with dementia experience may reflect the stigmatizing views of hierarchical sex acts since people with dementia are often viewed as a group who should not engage in sex. By intersectional challenges, I am referring to the injustices that some people may encounter because of their membership in oppressed groups. The concept of intersectionality originated in 1989 with the work of Kimberle Crenshaw who argued that the intersection of race and sex are relevant to the unjust experiences of Black women.⁷⁹ Shannon Dea describes intersectionality in the following way:

People are advantaged or disadvantaged because of their gender, race, ethnicity, class, sexual orientation, religion, disability, citizenship, etc. For instance, I experience some disadvantage because I am a woman who grew up in the working class. However, I enjoy privileges associated with being straight and white. While a Black lesbian and I are both

⁷⁸ Rubin, *Deviations*, 149.

⁷⁹ Kimberle Crenshaw, "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics," *University of Chicago Legal Forum* 1, no. 8 (1989): 139-167.

subject to some discrimination because of our gender, she is subject to further discrimination due to her race and sexual orientation.⁸⁰

Intersectionality is relevant to the topic of sex and consent for people with dementia. There are many intersectional challenges that will be important to consider, some of which have to do with common perceptions and stereotypes of sex and disability, age, race, and gender. I consider some possible intersectional challenges that may be relevant to the topic of sex and dementia below. It is important to note, however, that not everyone who identifies as a member of any of the below groups will necessarily have similar sexual experiences and/or challenges. Also, the below challenges are not meant to serve as an exhaustive list.

One of the most prominent intersectional challenges to keep in mind throughout this dissertation applies to people with dementia who are also elderly. Although it is not necessarily the case that someone with dementia is elderly, the majority of people with dementia are older than sixty-five, and when they *are* older then they will plausibly experience additional challenges when it comes to sex.⁸¹ The reason that sex poses a challenge when it comes to those who are elderly is because of widespread ageist stereotypes that exist in Western (and potentially non-Western) societies.⁸² In his book on the ethics of aging, de Lange says that old age is seen as “horrific, disgusting, and tainted by mortality.”⁸³ Erotic love “seems to be mostly out of place when it comes to the elderly. Old age and ‘eroticism’ hardly seem to go together. Rather, old age

⁸⁰ Shannon Dea, *Beyond the Binary: Thinking about Sex and Gender* (Peterborough: Broadview Press, 2016), 17.

⁸¹ Alzheimer Society of Canada, “Young Onset Dementia,” February 7, 2018, accessed March 22, 2018, <http://www.alzheimer.ca/en/About-dementia/Dementias/young-onset-dementia>.

⁸² Gayle Appel Doll, *Sexuality and Long-Term Care* (Baltimore: Health Professions Press, 2012), 45; de Lange, *Loving Later Life*, 62 and 68; de Lange says that aging is viewed as a negative process in Japan.

⁸³ de Lange, *Loving Later Life*, 62.

often fills us, especially young people, with feelings of disgust.”⁸⁴ Older individuals are often judged by different standards of acceptable behaviours when compared to younger populations, especially when they are diagnosed with dementia. Some of the challenges that may arise for older people with dementia are described in Mitchell, Dupuis, and Kontos’s discussion of the troubling discourse that is used to describe dementia. The authors suggest that “the losses experienced [from a dementia diagnosis] are far more profound when experienced within a totalizing culture that stigmatizes aging and dementia and leads to dehumanizing practices such as objectification, exclusion, silencing and so forth.”⁸⁵

Along the same line of thought, Merryn Gott and Sharron Hinchliff say that “[s]tereotypes of an asexual old age remain pervasive, shaping not only popular images of older people, but also research and policy agendas.”⁸⁶ However, these stereotypes have been contested in recent studies. Gott and Hinchliff’s study considered quality of life assessments and in-depth interviews with forty-four participants between the ages of fifty and ninety-two. They concluded that “sex is seen as an important component of a close emotional relationship in later life.”⁸⁷ As stated by one seventy-six-year-old participant, “It’s physical problems that make your sex life less really, not the actual needs and wanting.”⁸⁸ Another participant, aged seventy-one, discussed her use of sex aids in order to satisfy her sexual desires (mostly as a result of her husband’s erectile dysfunction and his lack of sexual interest). Although participants in their seventies and

⁸⁴ de Lange, *Loving Later Life*, 109.

⁸⁵ Mitchell, Dupuis, and Kontos, “Dementia Discourse: From Imposed Suffering to Knowing Other-Wise,” 6.

⁸⁶ Merryn Gott and Sharron Hinchliff, “How important is sex in later life? The views of older people,” *Social Science & Medicine* 56, (2003): 1617.

⁸⁷ Gott and Hinchliff, “How important is sex in later life? The views of older people,” 1626.

⁸⁸ Gott and Hinchliff, “How important is sex in later life? The views of older people,” 1623.

eighties ranked sex as less important than participants in their fifties and sixties, “this was not attributed to age per se. Rather the prevalence of those barriers that resulted in the reprioritisation of sex increased, and became more insurmountable, with it.”⁸⁹

John DeLamater and Sara M. Moorman performed a similar study involving 1384 people over the age of forty-five. They discovered that more than one quarter of couples aged seventy-five and older had sex at least once a month.⁹⁰ Asgeir R. Helgason et al. completed a study that explored elderly Swedish men’s interest in preserving their sexual capacity, and eighty-three percent of the 319 men said that maintaining their capacity to have sex was very important.⁹¹ The median age of the men in this study was sixty-eight. In another study, Judy G. Bretschneider and Norma L. McCoy studied the prevalence of sexual activities of 100 white men and 102 white women living in a California retirement home. They found that sixty-two percent of men and thirty percent of women over the age of eighty had sexual intercourse sometimes, and eighty-three percent of men and sixty-four percent of women engaged in some form of physical intimacy without intercourse.⁹² Moreover, they found that “[p]ast importance of sex was significantly correlated with present frequency and enjoyment of both sexual intercourse and touching and caressing without sexual intercourse.”⁹³ While all of these studies offer empirical evidence to refute existing stereotypes about aging and sexual interests, these stereotypes are still prevalent.

⁸⁹ Gott and Hinchcliff, “How important is sex in later life? The views of older people,” 1626.

⁹⁰ John DeLamater and Sara M. Moorman, “Sexual Behavior in Later Life,” *Journal of Aging and Health* 19, no. 6 (2007): 922.

⁹¹ Asgeir R. Helgason et al., “Sexual Desire, Erection, Orgasm and Ejaculatory Functions and Their Importance to Elderly Swedish Men: A Population-based Study,” *Age and Ageing* 25, (1996): 285.

⁹² Judy G. Bretschneider and Norma L. McCoy, “Sexual Interest and Behavior in Healthy 80- to 102-Year-Olds,” *Archives of Sexual Behavior* 17, no. 2 (1988): 116.

⁹³ Bretschneider and McCoy, “Sexual Interest and Behavior in Healthy 80- to 102-Year-Olds,” 109.

A related stereotype that contributes to this type of intersectional challenge involves perceptions of sex and disability since “[d]isabled people’s sexuality is [often] regarded as also somehow disabled.”⁹⁴ In her discussion on structural barriers and sexual autonomy for people with disabilities, Bethany Stevens says that persons with disabilities encounter structural and attitudinal barriers when it comes to sexual autonomy.⁹⁵ Sexual activity is often denied for people who are disabled and cared for by others.⁹⁶ The term “cripsex” is sometimes used to draw attention to this inequity and to advocate for sexual autonomy for people with disabilities. The term “uses the political power of the shortened (from cripple) and reclaimed the word “crip” to express the political nature of the sexuality of disabled people.”⁹⁷ According to the World Health Organization, dementia causes disability and dependency, and some dementia advocates have recently argued that dementia should be classified as a disability itself.⁹⁸ Given that dementia is seen to cause disability and dependency, perspectives regarding sex and disability (both cognitive and physical) are important to keep in mind.

Dementia is a cognitive impairment, and as I have discussed, people with cognitive impairments are often recognized as non-sexual and were historically de-sexualized because of

⁹⁴ Tomasz Sikora and Dominika Ferens. “Introduction: Let’s Talk About (Crip) Sex,” *a journal of queer studies*, special edition: ugly bodies, queer perspectives on illness, disability and aging, no. 11a, (2016).

⁹⁵ Bethany Stevens, “Structural Barriers to Sexual Autonomy for Disabled People,” *Human Rights* 38, no. 2 (Spring 2011): 14.

⁹⁶ Stevens, “Structural Barriers to Sexual Autonomy for Disabled People,” 16.

⁹⁷ Stevens, “Structural Barriers to Sexual Autonomy for Disabled People,” 16.

⁹⁸ World Health Organization, “Dementia”, 2017, accessed March 23, 2018, <http://www.who.int/mediacentre/factsheets/fs362/en/>; Philly Hare, “Why viewing dementia as a disability could be helpful to everyone,” *dementia without walls*, 2017, accessed March 23, 2018, <http://dementiawithoutwalls.org.uk/2017/05/why-viewing-dementia-as-a-disability-could-be-helpful-to-everyone/>.

this stereotype.⁹⁹ Similarly, Michael Gill claims that “those with intellectual disabilities are often assumed to be incompetent and unable to make meaningful decisions in their lives, let alone make and execute sexually fulfilling choices.”¹⁰⁰ A historical example of how people with cognitive impairments have been de-sexualized occurred in psychiatric institutions, where men and women were segregated with the goal of preventing sexual relations.¹⁰¹ Similar stereotypes exist when we look to the broader disability studies literature. In *Sex and Disability*, Anna Mallow and Robert McRuer say “when sex and disability are linked in contemporary American cultures, the conjunction is most often the occasion for marginalization or marveling: the sexuality of disabled people is typically depicted in terms of either tragic deficiency or freakish excess.”¹⁰² This stereotype is reinforced by the way that people with dementia are typically regarded as either non-sexual or hypersexual.¹⁰³ Hypersexuality is sometimes referred to as “sexual disinhibitedness” or “sexual inappropriateness.”¹⁰⁴ Given that both elderly persons and people with disabilities are often seen as non-sexual, older people with dementia will probably

⁹⁹ Andria Bianchi, “Autonomy, Sexuality, and Intellectual Disability,” *Social Philosophy Today* 32, (2016), doi: 10.5840/socphiltoday20168232.

¹⁰⁰ Michael Gill, *Already Doing It: Intellectual Disability and Sexual Agency* (Minneapolis: University of Minnesota Press, 2015), 10.

¹⁰¹ E.M. Cort, J. Attenborough, and J.P. Watson, “An initial exploration of community mental health nurses’ attitudes to and experience of sexuality-related issues in their work with people experiencing mental health problems,” *Journal of Psychiatric and Mental Health Nursing* 8, (2001): 490.

¹⁰² Robert McRuer and Anna Mollow, eds., *Sex and Disability* (United States of America: Duke University Press, 2012), 1.

¹⁰³ Hypersexuality is a relatively uncommon symptom of dementia. Approximately 2-17% of people with dementia are considered to be “sexually disinhibited”. See Hugh Series and Pilar Degano, “Hypersexuality in Dementia,” *Advances in Psychiatric Treatment* 11, no. 6 (2005).

¹⁰⁴ There is some scepticism about considering “hypersexuality” as a symptom of dementia. Some people consider hypersexual behaviours as simply indicative of a person’s interest to engage in sex—these behaviors may indicate a need that ought to be filled. This is a legitimate point to consider. However, for the purposes of this chapter I will assume that hypersexuality is a symptom of dementia in which a person might express hypersexual tendencies as something separate from the autonomous desire to engage in sex.

experience specific kinds of stigmatizing challenges when it comes to the topic of sex and consent, such as, for instance, being seen as non-sexual beings.

Another intersectional challenge that is important to keep in mind when it comes to the ethics of sex and consent is being a woman with dementia. As mentioned in the section above, one of the reasons that women may experience certain challenges when it comes to sexual consent (irrespective of a dementia diagnosis) is because of the patriarchal society in which sexual practices may exist, where “men hold sexual power and women are expected to be compliant.”¹⁰⁵ Estrich’s book focuses on women who are sexually assaulted by men because they are assaulted at an exponentially higher rate. She says that “rape—or whatever it is called—is not a gender-neutral crime. The empirical reality is that men rape, not women. Power and powerlessness are not gender neutral in our society. When women are the victims, gender is an issue that should not be avoided.”¹⁰⁶ Carol Pateman makes a similar point when she says that a “special problem” exists when it comes to women and consent because of what she calls the “sexual double standard,” where women are seen as naturally subordinate in comparison to men and they are socialized to behave passively.¹⁰⁷ If women are socialized to behave in passive and compliant ways such that their ability to consent/refuse to consent to sex is compromised, then these socialized behaviours, alongside those of people with dementia (in which they are expected to be obedient) may be problematic.¹⁰⁸

¹⁰⁵ Pamela Haag, *Consent: Sexual Rights and the Transformation of American Liberalism* (London: Cornell University Press, 1999), xvii; Linda R. Hirschman and Jane E. Larson, *Hard Bargains: The Politics of Sex* (New York: Oxford University Press, 1998); Shrage and Stewart, *Philosophizing About Sex*.

¹⁰⁶ Estrich, *Real Rape*, 82.

¹⁰⁷ Pateman, “Women and Consent,” 164.

¹⁰⁸ Ellen Bouchard Ryan, Mary Lee Hummert, and Linda H. Boich, “Communication Predicaments of Aging: Patronizing Behavior toward Older Adults,” *Journal of Language and Social Psychology* 14, no. 1-2 (1995), doi: 10.1177/0261927X95141008.

There may be some reason to believe that the challenges that some women encounter when it comes to consenting/refusing to consent to sex may be especially important for women who are members of other marginalized groups. The types of women that I am thinking of are those who are visible minorities, economically disadvantaged, and/or living with a disability.¹⁰⁹ Although the aim of prior feminist movements was to liberate all women, one criticism of the movement is that it managed to silence many women who were not white and in the middle class, thereby exacerbating their oppressive experiences.¹¹⁰ Furthermore, as stated by Marina Oshana, “[s]ome women engage in practices of gender hierarchy because they belong to cultural or religious groups that endorse such practices. For these women, engaging in practices of gender hierarchy is an integral and important part of their social identities.”¹¹¹ Insofar as these social identities have the possibility to influence sexual identities, then this may pose a problem when it comes to one’s ability to autonomously consent to sex—the idea is that a person cannot be autonomous and subordinate to another person at the same time.

If certain conceptions of autonomy are essential for sexual consent, then women who are subordinate and potentially non-autonomous would be unable to consent. So, if the pressure to exhibit certain social behaviours influences women’s sexual experiences, especially for women who are not white and in the middle class, and if these experiences influence a person’s sexual behaviors upon being diagnosed with dementia, then people with these intersecting identities may experience exacerbated vulnerabilities and the need to protect them from undue harm may,

¹⁰⁹ Barbara Cassidy, Robina Lord, and Nancy Mandell, “Silenced and Forgotten Women: Race, Poverty, and Disability,” in *Feminist Issues: Race, Class, and Sexuality*, ed. Nancy Mandell (Scarborough: Prentice-Hall Canada, 1998).

¹¹⁰ Cassidy, Lord, and Mandell, “Silenced and Forgotten Women: Race, Poverty, and Disability,” 48; Dea, *Beyond the Binary*, 17.

¹¹¹ Jennifer Warriner, “Gender Oppression and Weak Substantive Theories of Autonomy,” in *Personal Autonomy and Social Oppression: Philosophical Perspectives*, ed. Marina Oshana (New York: Routledge, 2015), 26.

consequently, increase. The reason that dementia may exacerbate the possibility of harm for people of certain social identities is because of some of the symptoms of a dementia diagnosis. For instance, while a person who engages in a practice of gender hierarchy may be seen as non-autonomous from some perspectives, they would probably still be *capable* of communicating preferences, reporting harmful experiences, accessing support services, articulating different perspectives, changing their minds, etc. These capabilities can help when it comes to protecting oneself from harm and (re)gaining/increasing autonomy. However, people with dementia may not have these capabilities because of their symptoms. They may not be able to articulate new perspectives, express conflicting preferences, identify abuse, etc.

The intersection of race and gender or “gendered racial identity development”¹¹² will also be important to keep in mind. Gendered racial identity is a type of social identity, and a social identity is “the part of an individual’s self-concept that derives from knowledge of membership in a group along with the emotional significance attached to it.”¹¹³ This is why some people who identify as members of certain groups experience positive social identity and members of other groups hold negative and oppressive sentiments, and these sentiments may influence a person’s behaviour in sexual and non-sexual contexts. In her discussion of rape, Cahill says that “rapes that occur between differently raced people can have a host of meanings that are not necessarily present in rapes that occur between people of the same race.”¹¹⁴ If a person has experienced and been influenced by certain racial stereotypes (both in and outside of the sexual domain) then their experiences of sex may differ from others’. For instance, Black women experience higher

¹¹² Anita Jones Thomas, Jason Daniel Hacker, and Denada Hoxha, “Gendered Racial Identity of Black Young Women,” *Sex Roles* 64 (2011): 532.

¹¹³ Thomas, Hacker, and Hoxha, “Gendered Racial Identity of Black Young Women,” 530.

¹¹⁴ Cahill, *Rethinking Rape*, 115.

rates of both petty harassment (e.g. being picked on) and sexual harassment in comparison to their white counterparts. Furthermore, a stereotype exists in which Black women are often expected to serve others and to behave in sexually promiscuous ways, while at the same time being “socialized to appear strong, tough, resilient, and self-sufficient.”¹¹⁵ Because of the perceived need to act in accordance with this “Strong Independent Black Woman”¹¹⁶ stereotype, the likelihood of Black women reporting sexually abusive experiences is low. Due to this oppressive narrative, Black women tend to be at a higher risk for sexually transmitted infections in comparison to white women, and they tend to have more sexual partners (both consensual and non-consensual).¹¹⁷

It is also the case that Black men may be more likely to be accused of sexual assault as opposed to their white counterparts. There is a long history in the United States of Black men being incorrectly accused of raping white women.¹¹⁸ In her analysis of sexual assault, Estrich discusses cases of men who were convicted of sexually assaulting women. Many of the men in these cases were eventually found to be innocent (their convictions were reversed) because of a lack of resistance by the woman involved. These cases occurred during a time when forcefulness and resistance were legally relevant to consent. However, Estrich says that “one is hard pressed to find a conviction of a stranger, let alone a black stranger, who jumped from the bushes and attacked a virtuous white woman, reversed for lack of resistance, even though the woman reacted

¹¹⁵ Thomas, Hacker, and Hoxha, “Gendered Racial Identity of Black Young Women,” 532 ; Kumea Shorter-Gooden and Leslie C. Jackson, “The interweaving of cultural and intrapsychic issues in the therapeutic relationship,” in *Psychotherapy with African American women: Innovations in psychodynamic perspectives*, ed. Leslie C. Jackson and Beverly Greene (New York: Guilford, 2000), 15–32.

¹¹⁶ Thomas, Hacker, and Hoxha, “Gendered Racial Identity of Black Young Women,” 532.

¹¹⁷ Tina M. Timm, et al., “Sexual Debut of Young Black Women Who Have Sex With Women: Implications for STI/HIV Risk,” *Youth & Society* 45, no. 2 (2011): 167-183.

¹¹⁸ Cahill, *Rethinking Rape*, 116.

exactly as the women did in [similar cases involving white men].”¹¹⁹ This may have something to do with the stereotype that Black men are seen as sexually aggressive. Insofar as this stereotype still exists then it seems possible that Black men with dementia who engage in sex with women (especially, perhaps, white women) may be seen in a predatory light and treated differently than white men with dementia.

When it comes to sex and consent, perspectives from queer theory will also be important to consider. Queer theory arose as a response to critical attitudes against certain identities, such as people who identified as part of the LGBTQ population.¹²⁰ Until 2003, thirteen states in the United States of America could (and did) criminalize sexual activities that were not heterosexual coitus, even if they were consensual and pleasurable. Only penis-vagina penetrative sex was permitted.¹²¹ This legal barrier was meant to deter LGBTQ people from engaging in the types of sex that accorded with their sexual preferences and identities, and this restriction motivated queer theorists to advocate for change. One of the primary goals of queer theorists was to extend “beyond the simple “gay/straight” split”¹²² and allow for various constructions of gender and sexual identity. Some of the challenges that have been and are experienced by members of this community in relation to sexual acts will be relevant to considering people with dementia who fit under the queer umbrella. For instance, while Black men are often portrayed as sexually aggressive, the stereotype is exacerbated for Black men in the gay community.¹²³

¹¹⁹ Estrich, *Real Rape*, 32.

¹²⁰ Marino, “Philosophy of Sex.”

¹²¹ Stevens, “Structural Barriers to Sexual Autonomy for Disabled People,” 14.

¹²² Cassidy, Lord, and Mandell, “Silenced and Forgotten Women: Race, Poverty, and Disability,” 71; Dea, *Beyond the Binary: Thinking About Sex and Gender*.

¹²³ Neils Teunis, “Sexual objectification and the construction of whiteness in the gay male community,” *Culture, Health & Sexuality* 9, no. 3 (May-June 2007): 271.

Also, queercrip theory may be relevant to some of the experiences of people with dementia. The theory “speaks to the unique experiences of queer disabled people that were not adequately addressed by queer or disability theories separately.”¹²⁴ An LGBTQ person with a physical or cognitive disability would fall under this category. LGBTQ people with disabilities have been referred to as a “minority within a minority”¹²⁵ who experience a “layered stigma”¹²⁶ of oppression. Similar kinds of experiences may occur for LGBTQ people with dementia.

In his 2007 study on sexual objectification in the gay community, Neils Teunis interviewed gay African American men in California. His study showed that African American men are often expected to perform potentially oppressive roles upon engaging in sexual interactions with white men. Teunis says that “[i]deologies of inclusivity and non-discrimination blind white gay men to the harmful effects of sexual objectification”¹²⁷ where “[t]he sexual objectification of men of colour forces them to play specific roles in sexual encounters that are not necessarily of their own choosing.”¹²⁸ Teunis’s study found that many gay men in San Francisco understand their sexuality in terms of the position they take when they are having sex. There are three sexual position possibilities: top, bottom, or versatile. The role of the person on top is to please the person on the bottom; the person on top is dominant and the person on the bottom is submissive—a person with a versatile sexual preference means that they are willing to engage in either of these options. While passivity and submissiveness are typically indicative of

¹²⁴ Alan Santinele Martino, “Crippling sexualities: An analytic review of theoretical and empirical writing on the intersection of disabilities and sexualities,” *Sociology Compass* 11, (2017): 7, doi: 10.1111/soc4.12471.

¹²⁵ Martino, “Crippling sexualities: An analytic review of theoretical and empirical writing on the intersection of disabilities and sexualities,” 2.

¹²⁶ Martino, “Crippling sexualities: An analytic review of theoretical and empirical writing on the intersection of disabilities and sexualities,” 2.

¹²⁷ Teunis, “Sexual objectification and the construction of whiteness in the gay male community,” 263.

¹²⁸ Teunis, “Sexual objectification and the construction of whiteness in the gay male community,” 263.

non-autonomy when it comes to women, the submissive person on the bottom of a sexual interaction between gay men represents the person who is in control. As stated by Teunis, “the bottom is actually the powerful one in the relationship, the one who establishes boundaries and expects to receive sexual pleasure, even at the expense of the top, if necessary.”¹²⁹

According to Teunis, African American men are often expected to maintain a top position when having sex with white men. Part of the reason for this expectation is to illustrate the stereotype of “the sexually aggressive black man, which appeals to the sexual fantasy of many white men.”¹³⁰ During Teunis’s interviews, “[a]ll but one of the African American men spoken with report that they invariably are put in a top position when they have sex with white men. They often indicate that they are more versatile by preference or even bottoms, but such a role is seemingly not available to them.”¹³¹ Similar kinds of stereotypes, discriminatory attitudes, and sexual role limitations exist for other people who identify as LGBTQ, such as the “kinky” sexual practices that are sometimes expected to exist as a part of sexual socialization for lesbians.¹³² If members of the queer community encounter challenges when it comes to stereotypes about their sexual identity and making autonomous sexual decisions, as well as other factors such as simple homophobia, then these stereotypes and any associated complexities must be appropriately considered for those who are later diagnosed with dementia.

As mentioned in the Introduction, this dissertation aims to consider different ways to approach sexual consent for people with dementia while at the same time recognizing the very real and important need to protect them from undue harm. This need to protect people from

¹²⁹ Teunis, “Sexual objectification and the construction of whiteness in the gay male community,” 270.

¹³⁰ Teunis, “Sexual objectification and the construction of whiteness in the gay male community,” 274.

¹³¹ Teunis, “Sexual objectification and the construction of whiteness in the gay male community,” 270.

¹³² Cassidy, Lord, and Mandell, “Silenced and Forgotten Women: Race, Poverty, and Disability,” 67.

experiencing undue harm is supported by the ethical principle of non-maleficence.¹³³ In performing this task, is important to realize that some people with dementia who are members of certain identity groups may experience intersectional challenges, and some of these challenges may increase an individual's risk of experiencing undue harm. It will be impossible to consider all of the possible challenges that people with dementia may experience by virtue of being associated with certain groups or populations. I will at times, however, flag certain complexities that ought to be considered in the chapters moving forward.

6- Conclusions

Many challenging factors are pertinent to considering the topic of sex for people with dementia. The most prevalent factor is that of sexual consent since people with dementia are often unable to consent in typical ways due to the symptoms that are associated with dementia. Consent is recognized as a standard for determining ethically licit versus ethically illicit sexual behaviours. This chapter described the moral and legal significance of sexual consent.

After introducing the importance of consent, this chapter outlined a few different models of sexual consent. These models respond to the normative question of how people ought to consent to sex/what consent ought to look like. It seems plausible that certain models of consent may be more helpful for certain populations, depending on the characteristics and historical circumstances of the people involved. The relevance and potential challenges of each of these models as applied to people with dementia will become clearer in the subsequent chapter, which considers applied cases of sex and people with dementia.

Intersectional challenges present some additional complexities that will need to be kept in mind throughout dissertation. Intersectional challenges are the challenges that are experienced by

¹³³ Beauchamp and Childress, *Principles of Biomedical Ethics*.

people who identify as members of certain marginalized populations; some of these challenges may influence their sexual experiences and capacity to consent to sex. For instance, both women and LGBTQ people with dementia may experience distinct sexual challenges that stem from their oppressive narratives (e.g. being socialized to be passive and agreeable when it comes to sex). These narratives are relevant to sexual consent in general, and they may be exacerbated for some people with dementia.

Now that the importance of sexual consent has been discussed, as well as some of the challenging factors of sex, consent, and dementia, the next step is to consider some applied cases that illustrate these complexities. The next chapter will present some cases of sex and people with dementia. The purpose of illustrating these cases is to showcase the difficulty in managing some of the challenges outlined above, such as the fact that many people with dementia cannot consent in accordance with current laws and proposed models. While some of these cases incorporate specific intersectional challenges that will be mentioned accordingly, all of them are complicated because people with dementia cannot consent to sex in typical ways.

Chapter 2

Cases of Sex and Dementia

The significance of sexual consent, as described in the previous chapter, is widely agreed upon in Western liberal societies. However, the law does not explicitly state how consent ought to be communicated and/or interpreted by participating parties. In order to respond to this normative question regarding what consent ought to involve, different models of sexual consent have been proposed. The “no’ means no” and affirmative consent models of sexual consent are the most prevalent. These models are meant to ensure that people can autonomously consent to sex and accurately interpret a person’s consent. The potential problem, however, is that people with dementia may be unable to accord with these models because of their symptoms.

Considering sex and sexuality is an essential part of being human, it is likely that many people will want to engage in sex at various stages of their life, including older individuals who are diagnosed with dementia.¹ In her discussion of sexuality and elderly people, Belinda Kessel says that people continue to participate in sexual acts until their late eighties and early nineties.² There are many studies that support this claim, some of which were described in the previous chapter. The problem with these studies is that they typically do not focus on people with dementia, thereby failing to help defeat the specific and prevalent stereotype that claims that people with dementia are non-sexual agents. The reason that people with dementia are not the focus of these studies may be because of the rigorous ethics approval that would be required in

¹ Daniela G. Franco, Jorge Cardoso, and Isabel Neto, “Attitudes Towards Affectivity and Sexuality of People with Intellectual Disability,” *Sex Disabil* 30, (2012): 262; Chris Quinn, Brenda Happell, and Graeme Browne 2011, “Talking or avoiding? Mental health nurses’ views about discussing sexual health with consumers,” *International Journal of Mental Health Nursing* 20, (2011): 21; Gill, *Already Doing It*.

² Belinda Kessel, “Sexuality in the older person,” *Age and Ageing* 30, no. 2 (2001): 121, doi: <https://doi.org/10.1093/ageing/30.2.121>.

order to pursue a study on this population, specifically since they may be unable to autonomously consent to participate.

In this chapter I will outline some applied cases that involve sex and people with dementia. There are a few motivations for this discussion: (1) to show that people with dementia are sexually active; (2) to demonstrate that they may be unable to consent to sex in accordance with traditional models; (3) to showcase some of the relevant intersectional challenges mentioned in Chapter One; and (4) to consequently show that traditional ways of thinking about sex and dementia encounters certain limitations.

In the following section, I discuss some considerations about dementia that help to explain the types of cases that I am focusing on in this chapter. I then present and analyze five real-life cases of sex and dementia.

1- Dementia: Some Considerations

Throughout this dissertation and while assessing the cases below, it is important to keep in mind that dementia is typically seen as a progressive disease where moments of lucidity will often decrease over time. People in the early stages of dementia might be more autonomous and capable of consenting to sex compared to persons in the later stages. Their capacity to communicate and to understand the concept and potential consequences of sexual activities may still be intact.

In order to determine whether someone is in the early, middle, or late stages of dementia, healthcare providers often use the Global Deterioration Scale, sometimes called the Reisburg

Scale.³ The Global Deterioration Scale divides Alzheimer's disease (and other dementias) into seven categories based on a person's cognitive capacities. The seven categories are: (1) no cognitive decline (i.e., no problems with daily living); (2) very mild cognitive decline (i.e., forgets names, memory lapses); (3) mild cognitive decline (i.e., problem-solving difficulties, increasingly forgetful, organizational challenges); (4) moderate cognitive decline (i.e., difficulty with complex tasks); (5) moderately severe cognitive decline (i.e., requires help with clothing oneself, bathing, etc.); (6) severe cognitive decline (i.e., loss of awareness, unable to remember recent experiences, unable to care for oneself) and; (7) very severe cognitive decline (i.e., inability to eat by oneself, severe language impairment, unable to walk, etc.). People who are classified under numbers one or two on the Global Deterioration Scale would plausibly be seen as autonomous and capable of consenting to sexual acts and other activities. Those whose cognitive capacities fall between categories three to seven, however, may be seen as less able or unable to make autonomous decisions, especially decisions that are more complex (e.g. those that require increased concentration, problem-solving capacities, etc.).

As stated in the Introduction, all people with dementia can, and typically will, experience moments of lucidity throughout the course of their disease. So, while someone in the moderate-to-late stages of a dementia diagnosis may be unable to consent to sexual acts on most occasions, they may have moments of lucidity and be able to comprehend the activity to which they are participating. This poses some complex challenges that will be explored in subsequent chapters, such as cases in which someone with dementia has a moment of lucidity during sex.

³ Alzheimer Society of Canada, "Global Deterioration Scale," November 8, 2017, accessed March 23, 2018, <http://www.alzheimer.ca/en/About-dementia/Alzheimer-s-disease/Stages-of-Alzheimer-s-disease/Global-Deterioration-Scale>.

2- *Why Focus on Dementia?*

Some of the symptoms of a dementia diagnosis may be similar to those that are experienced by people with certain intellectual disabilities.⁴ For instance, some people with certain intellectual disabilities may experience challenges when it comes to language and communication skills, reasoning and judgement capacities, etc. As a result of these potential similarities, my focus on people with dementia may be seen as unjustifiably narrow.

In response to this possibility, however, there are a few noteworthy differences that exist between these two populations that explain why a narrow focus on people with dementia is defensible. In his discussion on sex and dementia, Peter Bartlett says that the topic of sex for people with intellectual disabilities differs from sex for people with dementia since the former group is typically seen as sexually active.⁵ While there are certainly stereotypes that exist in which people with intellectual disabilities are seen as non-sexual, these stereotypes are being actively defeated by advocacy groups. Moreover, educational workshops are being developed to teach people with intellectual disabilities about sexual acts so that they are able to make autonomous decisions about whether to consent.⁶ Rather than questioning whether people with

⁴ The Arc, "Intellectual Disability," 2016, accessed March 23, 2018, <https://www.thearc.org/learn-about/intellectual-disability>; This organization advocates for and provides services to people with intellectual disabilities. They say that an intellectual disability can be determined based on three characteristics. Someone with an intellectual disability will have: (1) An I.Q. between or below 70-75; (2) Limitations in adaptive behaviours (e.g. socialization, communication, daily activities, etc.) and; (3) Diagnosis of an intellectual disability prior to the age of 18.

⁵ Peter Bartlett, "Sex, Dementia, Capacity, and Care Homes," *Liverpool Law Review* 31, (2010): 137–154; Bartlett refers to this population as people with learning disabilities, but the term intellectual disability may better capture the broader community that he is referring to.

⁶ I have engaged in conversations about this topic in some of my applied ethics work. I currently sit on an ethics committee at an organization that provides support services to people with developmental disabilities. Many of the employees at this organization recognize their clients as sexual beings and they work to educate them about what it means to engage in safe sexual activities, the potential consequences of sex, etc.

intellectual disabilities are sexual, the primary ethical question/concern is often whether or not they should have the right to become parents.⁷

On the other hand, however, older people, including those with dementia, are not expected to be sexually active. As mentioned in Chapter One, the topic of sex for elderly persons is often perceived as not to happen, to be humorous, or to be inappropriate and disgusting.⁸ Also, while people with intellectual disabilities are certainly vulnerable when it comes to instances of sexual abuse, people with dementia are especially vulnerable because they may fail to accurately remember whether a sexually abusive experience occurred (i.e., a sexual experience to which they did not consent).⁹ The failure to remember and/or to report abusive experiences may be particularly common among women with dementia, specifically women who are socialized to be passive and agreeable.¹⁰

Another important difference between these populations is that people with dementia will often have prior autonomous wishes and values that may conflict with their current sexual wishes. Comparing a person's prior wishes, values, and behaviours with their present decisions complicates matters in terms of whether people with dementia are *actually* consenting to certain sexual acts, specifically if their presently expressed desires differ from past preferences.¹¹ This is a unique aspect of sex for people with dementia that does not apply to those with intellectual

⁷ Bartlett, "Sex, Dementia, Capacity, and Care Homes."

⁸ Kessel, "Sexuality in the Older Person," 121; Bartlett, "Sex, Dementia, Capacity, and Care Homes," 141.

⁹ MaryLou Harrigan, "Older Adult Abuse and Dementia- A Literature Review," *Alzheimer's Society of Canada*, (December 2010), http://alzheimer.ca/sites/default/files/Files/national/Articles-lit-review/article_elderabuse_2011_e.pdf.

¹⁰ Harrigan, "Older Adult Abuse and Dementia- A Literature Review."

¹¹ For instance, if a woman with dementia is interested in having sex with their prior monogamous partner then it may be easier to perceive this as a more legitimate/less questionable consent since it aligns with past desires and values. However, if this person with dementia wants to engage in sex with someone other than their partner then the legitimacy of this interest may be more easily questioned.

disabilities. Given these noteworthy differences, a narrow focus on persons with dementia is reasonable even though there may be some similarities regarding their capacity to consent to sexual acts at certain times.

Case #1: Peter Adcock

One of the first publicly reported cases involving dementia and sex occurred in a care home for senior citizens in 2010.¹² This was the case of *R v. Adcock*. In this case, the husband of a resident, Peter Adcock, was discovered to be engaging in sexual acts with a woman who lived at the home. The woman was not his wife, she was diagnosed with dementia, and she had a history of sexual disinhibitedness.

During the sexual encounters between Peter and the resident, the care home staff noticed that both participants were smiling; they seemed to be enjoying themselves. The sexual acts did not involve penetration and there was no evidence of any physical or emotional harm to the resident. Peter pleaded guilty to a charge of sexual offense for impeding the choice of a person with a mental disability. Given that no penetration occurred, he was sentenced to a maximum of four years in prison, which was reduced to three years on appeal. Part of the reason that Peter received a relatively light sentence was because he did not penetrate the resident, which would have resulted in a harsher sentence. Also, his previously innocent character and “the fact that his crime was one of acquiescence to the [uninformed] sexual request of the victim”¹³ prompted a lesser sentence.

¹² Bartlett, “Sex, Dementia, Capacity, and Care Homes,” 140.

¹³ Bartlett, “Sex, Dementia, Capacity, and Care Homes,” 140.

Case #2: Henry Rayhons

Another well-publicized case involving sex and dementia occurred in April 2015. In this case, 78-year-old Henry Rayhons faced a felony charge of sexual abuse for having sex with his wife, Donna, in her nursing home.¹⁴ The primary reason that he faced a felony charge was because Donna was unable to consent to sexual acts because of her Alzheimer's diagnosis and Henry continued to have sex with her. Upon learning about Henry and Donna's sexual relationship, the nursing home staff involved the police. Although he and his wife shared a loving relationship, the staff at the nursing home did not believe that Donna was capable of consenting to sex because of her dementia, and Henry thereby violated the law.

Henry was eventually found to be not guilty of sexual assault since Donna showed no signs of sexual abuse and staff members confirmed that she was always happy to see her husband. Additionally, Henry testified that his wife often initiated sex after her dementia diagnosis.¹⁵

Case #3: Windmill Manor

Another case occurred at Windmill Manor nursing home in Coralville, Iowa in 2009. In this case, two residents with dementia, a 78-year-old man who was divorced and an 87-year-old woman who was married, were found having sex. Upon discovering that they were engaging in sexual activities, the nurses immediately stopped them, to which the woman responded by "kicking, screaming, and biting the nurses."¹⁶ This woman was apparently much calmer and

¹⁴ Belluck, "Sex, Dementia and a Husband on Trial at Age 78."

¹⁵ Belluck, "Sex, Dementia and a Husband on Trial at Age 78."

¹⁶ Block, "Can Elderly Patients With Dementia Consent To Sex?"

happier when she was with the male resident, and forcing them to separate caused significant distress.

Similar to the previous case, there were no signs of sexual abuse. However, the woman would occasionally refer to her sexual partner by her husband's name. This poses the question of whether the woman actually wanted to engage in sex with this particular person. In response to this question, reporter Bryan Gruley said that "there are two schools of thought about this. One is that, you know, if they're that confused, how can they have the capacity to consent? And another school of thought is that these are people who've become, to some degree, somebody else."¹⁷ He expands on this perspective by also saying that "just because they confuse who they're with, that doesn't mean it doesn't give them some pleasure at a time in their lives when pleasure comes at a premium."¹⁸ The question of whether a person's present sexual desires and pleasure may be more important to consider in comparison to one's prior autonomous wishes in certain circumstances will be explored in Chapters Five and Six.

As a result of the case at Windmill Manor, three and a half years of regulatory prosecution occurred, the administrator and director of the nursing home were fired, the man and the woman were forced to avoid contact, and the man was eventually moved to another residence nearly two hours away.

Case #4: Same Sex Partners

The fourth case involving sex and people with dementia occurred in 1999 when a nursing assistant discovered two men with dementia in an assisted living facility having sex. In response

¹⁷ Block, "Can Elderly Patients With Dementia Consent To Sex?"

¹⁸ Block, "Can Elderly Patients With Dementia Consent To Sex?"

to this discovery, the nursing assistant immediately separated them and chastised one of the individuals by sending him to a psychiatric institution where he was put in restraints.¹⁹

Case #5: Justice O'Connor

Another case of sex and dementia involved former Supreme Court Justice Sandra Day O'Connor and her husband John O'Connor. When John was diagnosed with Alzheimer's, his cognitive capacities rapidly declined. He became depressed and introverted, and he could barely remember his family.²⁰ Upon being admitted into a nursing home, however, John fell in love with another resident. Justice O'Connor allowed her husband to pursue this new desired relationship since it contributed to significant pleasure and happiness for him. The reason that she had to *approve* of her husband's new relationship was because adultery was still a crime in twenty-three states at the time of John's case, and so one's married spouse had to approve of any outside-of-marriage relations to prevent one's partner from being convicted of adultery.²¹

The primary reason that Justice O'Connor was accepting of her husband's new relationship was because of the influence that it had on his overall happiness and well-being. Upon commencing this new relationship, John's depression subsided and he became much happier. It is unclear whether John and his new partner were engaging in a sexual relationship involving penetration. The only published information about this case discusses their romantic relationship that involved kissing and hand-holding. It seems plausible that Justice O'Connor

¹⁹ Perlin and Lynch, *Sexuality, Disability, and the Law: Beyond the Law Frontier?*, 79-80; this was the only same sex case that I learned about during my research and there was only a small amount of information available.

²⁰ Sherwell, "Judge lost husband to Alzheimer's - and love."

²¹ Now, adultery is a crime in 21 states; this is discussed by: Deborah L. Rhode, "Why is adultery still a crime?," *LA Times*, May 2, 2016, <http://www.latimes.com/opinion/op-ed/la-oe-rhode-decriminalize-adultery-20160429-story.html>); Evelyn Tenenbaum, "To Be or to Exist: Standards for Deciding Whether Dementia Patients in Nursing Homes Should Engage in Intimacy, Sex, and Adultery," *Indiana Law Review* 42, no. 3 (2009): 675.

may have approved of other intimate interactions if it contributed to her husband's happiness and well-being, however, since that appeared to be a primary decision-making motive.

3- Analysis

The above cases exemplify some of the potentially challenging factors involved in situations of sex and dementia. While there were legal consequences associated with many of these cases, they all present different factors for consideration when it comes to examining the ethics.

As mentioned in Chapter One, at least part of the reason that consent is seen as morally significant is because of the importance of respecting individuals' autonomous decisions. If the participating parties in cases 1-4 *were* able to autonomously consent to sex then any subsequent sexual acts may have been seen as ethically licit from the perspective of autonomy. For instance, if the resident involved with Peter Adcock had the capacity to autonomously decide to engage in sex and say "yes" or "no" in accordance with her decision, then they may have been allowed to proceed. It would have been important to respect their sexual decision(s) from an autonomy perspective.

Issues related to gender are also relevant to considering some of these cases above. Many of the cases involved women with dementia, and, as described in Chapter One, it can be challenging for some women to refuse to consent to sex because of the way that they are socialized to behave. Women with dementia may be even more vulnerable, especially if their partners are not cognitively impaired. For instance, although Henry Rayhons and his wife shared a loving relationship prior to her dementia diagnosis, it is possible that she may have been socialized to acquiesce to her husband's sexual requests irrespective of whether she was, in fact,

interested in participating (though, of course, in Henry Rayhons's case his wife supposedly initiated sexual requests), and if passively acquiescing to sex is not an autonomous choice, then it may be ethically concerning from an autonomy standpoint.

Another reason that issues of gender are important to consider is because women with dementia are less likely to remember and to report incidents of unwanted sex in comparison to men.²² If the principle of non-maleficence is considered when evaluating cases of sex and dementia (which seems important given the need to balance the right to sexual expression with protection from harm) then this information about remembering and reporting incidents of unwanted sex is relevant. Schulhofer argues that unwanted sex is a harm, and if women with dementia are more likely to participate in unwanted sex and less likely to report these kinds of sexual interactions, then this potential harm ought to be taken into account.²³ From the opposite perspective, however, the stereotype in which males are considered to be more sexually aggressive than women is also pertinent to many of the cases above.²⁴ In cases 1-3, for instance, the male partners were more forcefully reprimanded in comparison to their female counterparts. If this is in any way due to the gender stereotypes that are sometimes imposed on men, then this is concerning from a justice perspective since men may be treated unfairly due to these pervading assumptions.

Another reason that some of the cases are complex from an ethics standpoint is because some of the sexual partners were unaware of and/or did not seem to act in a way that aligned with their partners' prior autonomous sexual decisions and/or values. As will be discussed in Chapter Four, individuals' prior autonomous sexual preferences may be ethically relevant to

²² Harrigan, "Older Adult Abuse and Dementia- A Literature Review."

²³ Schulhofer, *Unwanted Sex*.

²⁴ Dea, *Beyond the Binary*.

considering sexual acts for people with dementia. The reason that prior autonomous decisions may be relevant is because of the principle of precedent autonomy. This principle suggests that a person's prior autonomous decisions ought to be respected as a matter of respecting autonomy if a person cannot make an autonomous choice at the present time. If prior autonomous decisions are important to consider and/or respect for people with dementia, then the sexual activities involved in cases 1, 3, 4, and 5 would be ethically concerning since the participants were unaware of their partners' prior autonomous sexual preferences (before their dementia diagnoses). Cases such as Henry Rayhons's may be less likely to encounter the same type of criticism since Henry Rayhons was, at least plausibly, aware of his wife's prior autonomous sexual preferences.

Additionally, the vulnerabilities and biases experienced by the LGBTQ population are applicable to case 4. While the men involved in this case may have been unable to autonomously consent to sex because of their dementia, the consequences that resulted from this case (in which both parties were prevented from seeing each other) may have been because of further biases around the ethics of heterosexual versus homosexual relations. If the nursing assistant held certain beliefs about the types of sexual partnerships that are ethically licit (in accordance with the hierarchical sex acts discussed in Chapter One), and if LGBTQ people were excluded from her view, then the sexual act that occurred amongst the two male residents would have been problematic from her perspective. In their discussion of sexuality and disability, Perlin and Lynch say that it is possible that certain care facilities may only allow heterosexual relationships to occur and/or homosexual activities between females, but not males, based on certain biases.²⁵

²⁵ Perlin and Lynch, *Sexuality, Disability, and the Law: Beyond the Law Frontier?*, 98.

The intersectional challenges that may be experienced by LGBTQ people with dementia are important to keep in mind given the biases and barriers that continue to exist for this population.

Additional challenges might come into play for gay men with dementia who are also members of certain racial backgrounds. In Chapter One I introduced Neils Teunis's study of sexual objectification and African American men in the gay community. In his discussion, Teunis says that problems of sexual objectification in the gay community are often ignored. Insofar as these problems continue to exist upon being diagnosed with dementia, then they ought to be taken into account since they may influence a person's capacity to make autonomous sexual decisions.²⁶ The description of case 4 does not specify the race of the participants, but it is important to mention the potential challenges that may be experienced for people in similar cases.

At least one reason that these practices and discriminatory attitudes might fail to allow for autonomous sexual decision-making is because they may result in adaptive preferences. There are lots of different theories of adaptive preferences—one theory is that adaptive preferences are preferences that individuals hold as a result of having a limited set of options; it is when people adapt their preferences to align with whatever options are presently available to them. Another theory is posed by Serene Khader, who defines adaptive preferences as: “(1) preferences inconsistent with basic flourishing that (2) are formed under conditions nonconductive to basic flourishing and (3) that we believe people might be persuaded to transform upon normative scrutiny of their preferences.”²⁷ In describing Khader's position, Catriona Mackenzie says that adaptive preferences “include preferences relating to gendered norms and practices with which

²⁶ Teunis, “Sexual objectification and the construction of whiteness in the gay male community.”

²⁷ Serene J. Khader, *Adaptive Preferences and Women's Empowerment* (New York: Oxford University Press, 2011), 41.

those subject to them seem to be complicity.”²⁸ This position is reinforced by Diana T. Sanchez et al., who say that the “[p]ressure to conform to gender norms, especially those that dictate powerlessness [like submissiveness], can diminish autonomy.”²⁹ For instance, suppose an underprivileged woman lives in a patriarchal society that allows women to have sex with only one person throughout their life; women who have more than one partner are jailed or killed. Now, suppose that this woman was in love with a poor farmer, but she was pursued by a wealthy businessman who aggressively forced her to engage in sex. She was not attracted to him and she did not enjoy being submissive in sex, which is how he forced her to behave. From this point on, the woman has a limited set of available options. She can: (1) not engage in sexual acts; (2) engage in sexual acts only with the wealthy businessman; or (3) engage in sexual acts with a new partner (e.g. the poor farmer) and risk being killed. If this woman convinces herself that she prefers to engage in sex with the wealthy businessman and maintain a submissive role in sex, then her preference might be adaptive in an autonomy-undermining sense. If she were able to make a fully autonomous choice, which would be the case if her social circumstances and situation were different, then she would not have the same preferences. Her preferences have been adapted to meet her currently available options.

It is typically thought that the people who are most likely to adapt their preferences are from oppressed and marginalized backgrounds, and there has been much debate in philosophical literature regarding whether adaptive preferences can, in fact, be autonomous. Adaptive preferences are sometimes seen as “autonomy deficits”. Khader argues, however, that it is a

²⁸ Catriona Mackenzie, “Responding to the Agency Dilemma: Autonomy, Adaptive Preferences, and Internalized Oppression,” in *Personal Autonomy and Social Oppression: Philosophical Perspectives*, ed. Marina Oshana (New York: Routledge, 2015), 49.

²⁹ Diana T. Sanchez, Amy K. Kiefer, and Oscar Ybarra, “Sexual Submissiveness in Women: Costs for Sexual Autonomy and Arousal,” *Personality and Social Psychology Bulletin* 32, no. 4 (2006): 513.

mistake to view adaptive preferences as autonomy deficits because “doing so implies that oppressed and deprived persons are not rational and cannot make their own decisions.”³⁰ Henry Richardson also thinks that adaptive preferences can be autonomous under certain circumstances.³¹ He says that if a person chooses to pursue an adaptive preference in order to protect themselves from harm or disappointment then they may be making an autonomous choice even if it is adaptive. The reason that this kind of adaptive preference may be autonomous is because “the importance of the good involved can combine with the instinctive protection of self-respect to maintain the autonomy of choice even though the agent deceives him-or herself about its rationale.”³² If a person decides to protect themselves by pursuing an option that is adaptive (in that it aligns with certain oppressive gender norms, for example) then it can be autonomous even if the person is self-deceived about it being adaptive.

If adaptive preferences have the possibility to inhibit women or people from the LGBTQ community (which are just two of the groups that are often seen to hold adaptive preferences) from making autonomous decisions, then this ought to be considered when evaluating the ethics of these cases. If, however, adaptive preferences do not, or do not always, mean that a person is unable to make autonomous choices (which is what Khader and Richardson suggest), then not all women or LGBTQ people with dementia will be inhibited from making autonomous sexual decisions. The topic of autonomy and adaptive preferences will only matter, of course, if autonomy is a relevant principle to consider upon assessing the ethics of cases of sex and dementia. If a person’s autonomy is not the most important principle to consider when it comes

³⁰ Mackenzie, “Responding to the Agency Dilemma: Autonomy, Adaptive Preferences, and Internalized Oppression,” 48.

³¹ Henry Richardson, “Autonomy’s Many Normative Presuppositions,” *American Philosophical Quarterly*, 38, no. 3 (July 2001): 287-303.

³² Richardson, “Autonomy’s Many Normative Presuppositions,” 293.

to sex and dementia, then the debate around autonomy and adaptive preferences is less significant.

Another important factor to consider in relation to the above cases is that some people with dementia are in committed monogamous relationships, and they may be unable to remember this commitment as a result of their cognitive decline. If the woman with dementia at the Windmill Manor did not have the capacity to make an autonomous decision regarding her commitment to her spouse (i.e., to decide whether she wanted to remain committed), then this would be ethically problematic from an autonomy perspective when it comes to considering the implications of her present (non-autonomous) desire to engage in a new relationship.

4- Conclusions

There are several challenging factors that are pertinent to considering cases of dementia and sex, many of which were illustrated above. One of the most prevalent challenges is that people with dementia are often seen as non-sexual beings. This is a false stereotype, and I hope that this stereotype has been at least somewhat disproven by describing these cases.

Sexual consent is the most important factor that influences how each of these cases are perceived since people with dementia are often unable to consent in accordance with legal and moral standards. Determining whether and/or how to enable people with dementia to consent to sex will be explored in subsequent chapters. If consent is important to assessing the ethics of sex for people with dementia, and insofar as sexual acts are at least somewhat important for this population, then considering different ways of enabling people with dementia to consent is important.

Now that some cases of sex and people with dementia have been introduced and briefly discussed, the next step is to consider some frameworks that may help us to approach similar kinds of cases moving forward. These frameworks respond to the primary challenge regarding the importance of sexual consent and people with dementia. Given that many, if not most, people with dementia are unable to consent in typical ways, we need to start thinking about how to respond to these cases. As stated in the Introduction, the purpose of these frameworks is to balance the right to sexuality with the protection from undue harm.

Chapter 3

A Framework of Relational Autonomy and Supported Decision-Making

In this chapter, I will consider what I am referring to as a framework of relational autonomy and supported decision-making as a potential way for people with dementia to autonomously decide to engage in sex. As demonstrated in Chapter One, the principle of autonomy is significant in Western liberal settings; being unable to make autonomous sexual decisions is ethically problematic from this perspective and people with dementia are often considered to be non-autonomous. This chapter suggests that a framework of relational autonomy and supported decision-making may enable persons with dementia to make autonomous sexual decisions with support.

In order to consider a framework of relational autonomy and supported decision-making, I will initially describe the history and relevance of relational autonomy in comparison to traditional conceptions of autonomy. I will then explain some accounts of relational autonomy, namely, procedural, substantive, and dialogical accounts. The primary reason that relational autonomy is the focus of this chapter is because relational autonomy accounts recognize that intersectional challenges may influence individuals' decision-making.

One problem with procedural, substantive, and dialogical accounts of autonomy is that some people with certain cognitive impairments may be regarded as non-autonomous, such as people with dementia. Being seen as non-autonomous is a problem for a couple of reasons. First, there are some significant practical consequences in our society for people who are not autonomous. Second, it seems that some people with certain cognitive impairments actually *are* autonomous and can make autonomous decisions with support. I have written about these

problems before, and I will reinforce some of my prior arguments in this chapter with a specific focus on persons with dementia.¹

After showing that people with dementia may not be seen as autonomous from the perspective of relational autonomy accounts, I will consider another approach that may regard people as capable of making autonomous decisions. The new approach that I consider is that of supported decision-making. Supported decision-making is a type of decision-making process that enables people to make autonomous decisions with support. This type of decision-making process is compatible with relational autonomy, as it recognizes that a person's decisions are not made in isolation. I discuss Alexander Boni-Saenz's and Laura Davy's accounts of relational autonomy and supported decision-making for people with cognitive impairments in this part of the chapter. Boni-Saenz's framework specifically focuses on sexual decision-making for people with dementia, making it especially relevant to this dissertation. Davy's framework is broader in that it considers all types of autonomous decisions for persons with intellectual disabilities. Ultimately, I find that there are certain limitations with both of these accounts. In response to these limitations, I expand on Boni-Saenz's and Davy's approaches and propose a modified framework of supported decision-making for people with dementia when it comes to sexual decisions.

The modified framework that I propose suggests that a sexual decision may only be seen as autonomous from the perspective of supported decision-making if it is consistent with other values and communicated preferences. The reason for this additional requirement is to try to ensure that people with dementia are making autonomous choices in the right way by minimizing the amount of undue influence that a person may encounter by those who are supporting their decisions. If the goal of relational autonomy and supported decision-making is to enable a person

¹ Bianchi, "Autonomy, Sexuality, and Intellectual Disability."

to make their own decisions about sexual acts, then we ought to ensure that they make decisions without being unduly influenced. Sex is a value-laden topic and a support network may impose their own sexual values onto a person with dementia, defeating the purpose of relational autonomy and supported decision-making as it currently stands. This modified framework may help to ensure that autonomous choices are being made. There are still some considerations and challenges to take into account when it comes to evaluating this framework, however, which I will introduce at the end of the chapter and in Chapter Six.

1- Relational Autonomy: A Historical Overview

As noted in Chapter One, the principle of autonomy is ethically and legally significant in Western societies. Historically, autonomy referred to being “one’s own person... directed by considerations, desires, conditions, and characteristics.”² Autonomy was based on ideas of self-determination and self-directedness, and a central figure who established this conception of autonomy was Kant.³ According to Kant’s moral philosophy, a person needed to possess practical reasoning skills and the capacity for self-determination in order to be autonomous.⁴

The above definition of autonomy as individual self-directedness has been criticized by some feminist philosophers as patriarchal because “such a conception of the self is associated with the claim that autonomous agents are, and ought to be, self-sufficient, which in turn is

² John Christman, "Autonomy in Moral and Political Philosophy," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta (Spring 2018 Edition), <https://plato.stanford.edu/archives/spr2018/entries/autonomy-moral/>.

³ Natalie Stoljar, "Feminist Perspectives on Autonomy," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta (Fall 2015 Edition), <https://plato.stanford.edu/archives/fall2015/entries/feminism-autonomy/>.

⁴ Mitchell, Dupuis, and Kontos, “Dementia Discourse: From Imposed Suffering to Knowing Other-Wise,” 3; The authors critique the idea that autonomous persons ought to be rational and have certain cognitive capacities. They do not discuss Kant specifically, but they seem to consider his ideas in their discussion of autonomy.

associated with the character ideal of the “self-made man”.⁵ One reason that this conception of autonomy reflects the ideal of a self-made man is, at least from some perspectives, that women are typically seen to value social relationships of care, and these types of relationships are perceived by some as incompatible with self-directedness and self-sufficiency.

In response to this patriarchal conception of autonomy, feminist philosophers reconfigured the definition. Some feminist interpretations of autonomy are now categorized under an umbrella term called “relational autonomy”. According to this new conception of autonomy, there are different ways of being autonomous; autonomy can be compatible with maintaining and valuing social relationships of care. In her discussion of autonomy, Catriona Mackenzie says that “personal autonomy is a relationally constituted capacity requiring extensive interpersonal, social, and institutional scaffolding.”⁶

Relational autonomy accounts are sometimes seen as similar to conceptions of shared agency, but in fact, they are importantly distinct. Shared agency considers the question of “what it is for us to act together”⁷ in a co-operative way. The aim of shared agency is to “be guided by reasons that are attributable, jointly, to *us*, as the product of a symmetrically shared deliberation.”⁸ Alternatively, relational autonomy is not focused on the “us” as a joined entity with shared intentions, but rather on independent individuals who are influenced by social

⁵ Stoljar, “Feminist Perspectives on Autonomy.”

⁶ Mackenzie, “Responding to the Agency Dilemma: Autonomy, Adaptive Preferences, and Internalized Oppression,” 48.

⁷ Andrea Westlund, “Autonomy in Relation”, in *Out from the Shadows*, ed. Sharon Crasnow and Anita Superson (New York: Oxford University Press, 2012), 61.

⁸ Westlund, “Autonomy in Relation,” 68.

contexts. Relational autonomy “takes up questions about how relations with others are implicated in one’s ability to act, not as a part of a collective, but as a singular agent.”⁹

The remainder of this chapter will only focus on relational autonomy as opposed to traditional conceptions of autonomy. The reason that accounts of relational autonomy will be considered is because they recognize an individual’s autonomy and autonomous decisions as inevitably influenced by their intersectional identities and the social contexts in which they live. Since sexual decisions are often, if not always, influenced by other individuals, a lens of relational autonomy will be the most apt perspective through which sexual acts and dementia ought to be considered (at least in comparison to traditional conceptions of autonomy). Sexual autonomy involves interacting with and getting support from others, making it such that any theory of autonomy that is based on complete self-sufficiency (e.g. Kant’s) is incompatible with sexual acts. Furthermore, relational autonomy “seek[s] to analyze how social oppression can impair the development and exercise of autonomy”¹⁰ and there are various contexts in which an individual’s oppressive experience(s) may influence their sexual choices and sexual autonomy; some of these circumstances were alluded to in previous chapters. For instance, a Black cisgender female living in a racist society may experience certain challenges when it comes to autonomous sexual decision-making if they possess an internalized sense of inferiority, as influenced by the society in which they live.¹¹ In her discussion on lesbian ethics, Maria Lugones says that “racism has several implications for agency... [such as] the difficulty of forming

⁹ Westlund, “Autonomy in Relation,” 61.

¹⁰ Mackenzie, “Responding to the Agency Dilemma: Autonomy, Adaptive Preferences, and Internalized Oppression,” 48.

¹¹ Maria Lugones, “Hispaneando y Lesbiando: On Sarah Hoagland’s Lesbian Ethics,” *Hypatia* 5, no. 3 (Fall 1990): 140; this was written as a review in response to: Sarah Lucia Hoagland, *Lesbian Ethics: Toward New Value* (California: Institute of Lesbian Studies, 1989).

intentions that are not formed in the mind of the racist.”¹² So, if a Black cisgender woman lives in a racist society and has always been treated as inferior, and if she has been encouraged to “respond with gratitude to being treated as people of any worth at all”¹³ then she may be more willing to submit to sexual advances from a white male even if she does not want to participate. Similarly, a lesbian Latina woman living in a colonized, racist, and heterosexualist Angloamerican culture may experience different types of challenges and pressures. Her sense of agency may be influenced by her social context and be relevant to her capacity to make autonomous choices when it comes to sex and other types of decisions.¹⁴ Intersectionality adds a layer of complexity to the already multifaceted topic of sexual decision-making, and a dementia diagnosis is just one of the intersections of a person’s identity that may be pertinent.

Relational autonomy has gained substantial uptake in philosophy over the past few decades, and different accounts of relational autonomy have been proposed. Each of these accounts recognizes autonomous individuals as capable of making decisions for themselves while at the same time being influenced by their social contexts. The accounts of relational autonomy differ in terms of how they define autonomy and what they specifically require for autonomous decision-making. I will discuss three kinds of relational autonomy accounts below: (1) procedural accounts of autonomy; (2) substantive accounts of autonomy; and (3) dialogical accounts of autonomy. I will describe these broad accounts of relational autonomy, as well as some of the sub-categories contained within the accounts.

Procedural accounts of autonomy gauge whether a person is autonomous based on their decision-making process as opposed to the content of particular decisions. Procedural accounts

¹² Lugones, “Hispaneando y Lesbiando: On Sarah Hoagland’s Lesbian Ethics,” 140.

¹³ Lugones, “Hispaneando y Lesbiando: On Sarah Hoagland’s Lesbian Ethics,” 140.

¹⁴ Lugones, “Hispaneando y Lesbiando: On Sarah Hoagland’s Lesbian Ethics,” 138.

are content-neutral. According to procedural theorists, “it is left up to the agents to determine how they might live, and this includes leading one’s life on the basis of values that endorse gender hierarchy. Proceduralism simply identifies a decision procedure for autonomy rather than a prescription for the good life.”¹⁵ According to proceduralist accounts, individuals are able to live their lives in accordance with their own values and still have the potential to be considered autonomous insofar as a particular decision-making process is followed; “there is no “right” value framework that an individual must endorse”¹⁶ in order to be autonomous.

The decisions that are considered autonomous from a procedural standpoint are those that involve a certain type of critical self-reflection. One procedural theorist is Diana Meyers, who says that a decision is autonomous insofar as it accords with people’s “dispositions of their authentic selves.”¹⁷ In order to ensure that a person makes decisions in accordance with their authentic selves, they must pursue a process of programmatic and episodic autonomy.

Programmatic autonomy involves a process of asking broad and comprehensive questions, such as “How do I want to live my life?”, “Do I want to have children?”, etc. If one critically reflects upon these questions and then makes decisions that align with one’s values and beliefs, then one can be seen as programmatically autonomous. Episodic autonomy involves a process of asking narrow and specific questions, such as “What do I want to do right now?”¹⁸ When one critically evaluates and approves of one’s episodic responses in relation to one’s beliefs and values then

¹⁵ Jennifer Warriner, “Gender Oppression and Weak Substantive Theories of Autonomy,” 29; Warriner thoroughly describes different types of autonomy, though she does not endorse a procedural account herself.

¹⁶ Warriner, “Gender Oppression and Weak Substantive Theories of Autonomy, 29.

¹⁷ Diana Meyers, “Personal Autonomy and the Paradox of Feminine Socialization,” *The Journal of Philosophy* 84, no. 11 (2008): 622, doi: <https://doi.org/10.5840/jphil198784117>.

¹⁸ Meyers, “Personal Autonomy and the Paradox of Feminine Socialization.”

one is seen as episodically autonomous. A person can come to realize their authentic selves through this process of episodic and programmatic autonomy.¹⁹

Marilyn Friedman provides an account of procedural autonomy that differs slightly from Meyers's. Friedman says that a person can be considered highly autonomous if they are able to thoroughly reflect on their decisions and ensure that their beliefs and desires are compatible with one another. For instance, if a person desires to attend a prestigious university but also wants to skip classes in high school (which results in them obtaining poor grades that will not get them accepted to a university program), then their desires are not compatible with one another and their decisions may be viewed as less autonomous on Friedman's account. According to Friedman, there are different levels of autonomy. An individual can be highly autonomous if their decisions are strongly compatible and less autonomous (or not autonomous at all) if their decisions do not coincide.

One of the primary advantages of procedural autonomy accounts is that people can make autonomous decisions that align with their personal values, beliefs, and goals. A focus on the decision-making process allows people to make autonomous choices that may be seen as "risky" or "bad" from some perspectives. For example, in a healthcare setting, procedural autonomy accounts would say that a person can autonomously choose to defer their decision-making authority to their spouse. If this decision is compatible with their other decisions and/or if it reflects their authentic self, then it would be autonomous from a proceduralist standpoint. This is advantageous since people can make decisions that reflect their individual preferences, irrespective of the content.

¹⁹ Meyers, "Personal Autonomy and the Paradox of Feminine Socialization"; These decisions will be influenced by relational factors. For example, a person's decision about whether they want to have children will plausibly be influenced by factors such as whether they have a supportive partner, whether their partner wants to have children, whether their boss at work offers them a promotion so they can financially support a child, etc.

Some theorists think that procedural accounts are too thin because “they do not put enough weight on the effects of internalized oppression on agents' motivational states.”²⁰ These critics suggest that the content of a person’s decision and the motivation for making certain decisions over others is relevant to whether a decision is autonomous. In contrast to procedural accounts, substantive accounts of autonomy “incorporate[s] content-laden, normative specifications about the social situation of the autonomous person or about the values and commitments she embraces.”²¹ So, whether or not an agent is autonomous depends in part on the content (or, substance) of their decision(s).

There are two different types of substantive accounts: weak accounts of substantive autonomy and strong accounts of substantive autonomy. Weak accounts require “agents to be [in] a certain self-referential psychological state”²² in order to be autonomous. For instance, a weak substantive account of autonomy might say that a person must have good self-esteem. The idea here is that if a person has low self-esteem then their decisions may be influenced by an autonomy-restricting psychological state (insofar as low self-esteem hinders autonomy). Paul Benson holds a weak substantivist account that focuses on a person’s ownership of their motives. According to Benson, a person is autonomous insofar as they have the capability to take ownership over what they do, to regard themselves as agents, and to exercise their capability of

²⁰ Stoljar, “Feminist Perspectives on Autonomy.”

²¹ Marina Oshana, “Is Social-Relational Autonomy a Plausible Ideal?,” in *Personal Autonomy and Social Oppression: Philosophical Perspectives*, ed. Marina Oshana (New York: Routledge, 2014), 3.

²² Oshana, “Is Social-Relational Autonomy a Plausible Ideal?,” 3.

owning their actions. A person can take ownership for their acts if they “stand in a certain position with respect to others’ potential expectations for one’s conduct.”²³

On the other hand, strong accounts of substantive autonomy are guided by the idea that “some ways of living are incompatible with autonomy”²⁴ because autonomy must be included among the things that a person values. An individual’s values “must accord with an ideal of autonomy.”²⁵ In her discussion of autonomy, Jennifer Warriner gives the example of women who are expected to be deferential based on certain religious traditions that subscribe to hierarchical gender roles, where women are supposed to “submit without question to their husbands’ authority in all important economic, social, familial, and sexual decisions.”²⁶ A person who supports these kinds of religious perspectives would not be autonomous from a strong substantive account in virtue of the content. Warriner argues that part of the reason that agreeing to maintain a subordinate or submissive role is non-autonomous is because subordinated people are given a certain “script” to follow; the script specifies the actions that subordinated people are permitted to pursue and it offers reasons to justify the actions. If a person does not consider themselves to be of an equal status to others and if they defer their decision-making authority to another party because they subscribe to a practice that tells them that it is the right thing to do, then any corresponding decisions would not be considered autonomous. Relational autonomy is based on the idea that autonomous decisions are self-directed even though they are influenced by social contexts. According to a strong account of substantive autonomy, a person cannot be

²³ Paul Benson, “Taking Ownership: Authority and Voice in Autonomy Agency,” in *Autonomy and the Challenges to Liberalism: New Essays*, ed. John Philip Christman and Joel Anderson (Cambridge: Cambridge University Press, 2005), 108.

²⁴ Warriner, “Gender Oppression and Weak Substantive Theories of Autonomy,” 29.

²⁵ Oshana, “Is Social-Relational Autonomy a Plausible Ideal?,” 3.

²⁶ Warriner, “Gender Oppression and Weak Substantive Theories of Autonomy,” 25.

autonomous if they defer their decision-making authority to another party which places them in a position that is subordinate. Strong substantive accounts of autonomy claim that “some ways of living are *incompatible* with autonomy, and living as a subordinated wife and (especially) as a slave seem to be *paradigmatic examples of these ways of living*.”²⁷

Dialogical accounts of autonomy respond to some theorists’ concerns that procedural and substantive accounts are too polarized. Dialogical accounts require people to be capable of justifying their decision(s) to themselves and others in order to be autonomous. In her discussion of dialogical autonomy, Andrea Westlund says that autonomy “depends upon a dialogical disposition to hold oneself answerable to external, critical perspectives.”²⁸ Her account is importantly distinct from strong substantive accounts of autonomy in that people *can* autonomously choose to be in deferential or submissive roles as long as they can explain the reasoning behind their decision(s). According to this account, an autonomous agent is one who has the ability to hold themselves answerable to their decisions even when they are critically challenged by others in light of social constructs. Westlund says that the disposition of holding oneself answerable to external perspectives “marks the relevant distinction between being gripped by and governing the practical reasoning that guides one’s actions.”²⁹

2- *Relational Autonomy and Dementia*

The above accounts of relational autonomy are based on the idea that individuals can make autonomous decisions while at the same time being influenced by their social circumstances. Theories of relational autonomy realize that autonomous agents do not live in

²⁷ Warriner, “Gender Oppression and Weak Substantive Theories of Autonomy,” 29, italics in original.

²⁸ Westlund, “Autonomy in Relation,” 60.

²⁹ Westlund, “Autonomy in Relation,” 65.

self-directed vacuums and are influenced by external relations. One problem with relational autonomy accounts, however, is that many people with dementia may still be seen as non-autonomous. I have made similar claims in previous work in regard to some people with certain intellectual disabilities.³⁰

As stated in Chapter Two, not everyone with dementia will experience the same symptoms during their illness trajectory. However, the common symptoms that many people with dementia will experience may inhibit their ability to make decisions that accord with relational autonomy accounts. For instance, if a person with dementia forgets their prior goals and values, then they may be unable to engage in a thorough and reflective decision-making process in accordance with their authentic selves; this is essential for procedural autonomy.³¹

Dementia can also cause reasoning and communication challenges.³² These symptoms may inhibit a person's capacity to justify their decision(s) and to communicate justifications to themselves and others; this may have been the case for many of the people discussed in Chapter Two. For instance, while Henry Rayhons's wife may have seemed happy to see her husband and/or to engage in intimate acts with him, she may have been unable to develop and communicate a rationale for her participation. If people with dementia cannot "hold [themselves] answerable to external, critical perspectives"³³ then they will not be seen as dialogically

³⁰ Bianchi, "Autonomy, Sexuality, and Intellectual Disability"; In this article, I argue that feminist conceptions of autonomy (relational accounts of autonomy) present challenges for people with intellectual disabilities. The reason that relational accounts are unhelpful in considering people with intellectual disabilities as autonomous is because some people with certain impairments may be unable to perform critical decision-making processes and/or unable to make decisions that are compatible with an ideal of autonomy. Both of these characteristics are incompatible with procedural and substantive accounts.

³¹ Alzheimer Society of Canada, "10 Warning Signs," February 13, 2018, accessed March 23, 2018, <http://www.alzheimer.ca/en/About-dementia/Alzheimer-s-disease/10-warning-signs>.

³² Alzheimer Society of Canada, "Ways to Communicate," January 23, 2018, accessed March 23, 2018, <http://www.alzheimer.ca/en/Living-with-dementia/Ways-to-communicate>.

³³ Westlund, "Autonomy in Relation," 60.

autonomous, and if autonomy matters, then this poses a barrier for people with dementia from this perspective.

Finally, a person with dementia may not be seen as autonomous from the perspective of substantive autonomy. Some people with dementia, especially frontotemporal dementia, may be more likely to engage in impulsive behaviours, and some of these behaviours may contain content that is problematic a substantive view. Furthermore, some people may defer all decision-making to their caregiver(s) and/or they may be more willing to submit to others' requests to engage in submissive acts. These kinds of deferent behaviours would be seen as non-autonomous from substantive autonomy accounts.

While this brief list of examples is far from exhaustive, it is meant to show that some of the symptoms of a dementia diagnosis may, in some circumstances, affect a person's perceived autonomy from relational autonomy accounts; this perceived lack of autonomy will translate to the sexual domain. For instance, a person with dementia will not be seen as procedurally autonomous if they are unable to engage in a critical decision-making process prior to making a sexual choice. If they are unable to explain their rationale or motive for making sexual decisions, then they will not be seen as dialogically autonomous. Finally, if a person with dementia agrees to maintain a deferent or submissive role, either because of their dementia and/or because of related social roles that intersect with their identity (which may have influenced their pre-dementia self), then this would be problematic from substantive autonomy views.

This final point about deciding to be deferent or submissive when it comes to sex and whether or not this kind of behaviour can be autonomous is pertinent to the topic of adaptive preferences. Adaptive preferences may be relevant to considering some people with dementia

and sexual decision-making from a substantive perspective, especially when it comes to people with dementia who are members of certain groups with a history of oppression.

As described in Chapter Two, adaptive preferences are the preferences that an individual may choose to hold when there are a minimal set of less than ideal options available; if other, better, options were made available then they would likely alter their preferences accordingly. Typically, adaptive preferences depict the preferences of individuals who have a limited set of potentially oppressive options available to them, such as, perhaps, a woman deciding to be submissive in sex. According to a strong substantive account of autonomy, it would be impossible for a person to autonomously choose to be submissive since submissiveness does not accord with an ideal of autonomy (similar to a deferential wife), especially insofar as submissiveness is an oppressive gender norm.

People of various backgrounds may have adaptive preferences, regardless of whether they have a dementia diagnosis. In her article “Autonomy and Male Dominance”, Marilyn Friedman offers a few examples of adaptive preferences. One of these examples considers women in abusive relationships. Friedman notes that in cases of extreme abuse, some women become complacent and convince themselves that they never really want the abuse to end.³⁴ In these cases, the victims adapt their preferences according to their circumstances; they probably would not have acquired a preference to be in an abusive (versus a non-abusive) relationship if their circumstances and options were different. Similarly, people with dementia may have adaptive preferences both in and outside of the sexual domain since they are often limited in the decisions that they can make—they may have to adapt their preferences based on a limited set of options that are not ideal. Many people with dementia, especially those who are in the later

³⁴ Friedman, “Autonomy and Male Dominance,” 153 and 159.

stages, are relatively socially powerless and vulnerable to the authority of others. Friedman says that “[s]omeone who is relatively socially powerless and therefore vulnerable to domination by a great many others... may become thoroughly adaptively malformed as a result”³⁵; this may be the case for many people with dementia if they cannot clearly communicate preferences, comprehend their position of vulnerability, say “no”, remember prior sexual values, etc.

The vulnerabilities associated with dementia when it comes to sex may be especially prevalent for certain sub-groups of the dementia population. One of these sub-groups may be women with dementia. A woman with dementia would probably identify as a member of at least two groups, namely the groups “woman” and “person with dementia”. Women are often socialized to behave in passive and/or deferential ways when it comes to sex (which may be referred to as socialized deference). Insofar as some women may convince themselves to prefer passivity and/or deference based on an oppressive circumstance in which there are a seemingly minimal set of options available, then their sexual preference(s) may be adaptive. As mentioned above, there are different perspectives about whether adaptive preferences are autonomous. In their discussion of women’s sexual submissiveness, Sanchez et al. say that “women learn to associate sex with female submission, an association that induces submissive sexual behavior... [and] submissive sexual behavior affords women less autonomy in the sexual context.”³⁶ These potentially non-autonomous behaviours may be exacerbated for women with dementia if they have even less decision-making authority due to their dementia symptoms. So, while a woman *without* dementia may be socialized to behave passively during sex, thereby potentially influencing her to make non-autonomous (adaptive) decisions (at least according to strong

³⁵ Friedman, “Autonomy and Male Dominance,” 158.

³⁶ Sanchez, Kiefer, and Ybarra, “Sexual Submissiveness in Women: Costs for Sexual Autonomy and Arousal,” 512.

substantive accounts of autonomy), a woman *with* dementia who is socialized to be passive and unable to communicate her preferences because of her symptoms may be even more likely to experience challenges when it comes to autonomous decision-making from a substantive view.³⁷

While women with dementia may be less likely than men to make autonomous sexual decisions according to strong substantive theorists, there are other groups who may also experience similar challenges. One of these groups is gay men of colour, as mentioned in Chapter One when we discussed Teunis's study.³⁸ There are no studies available on the sexual experiences of gay Black men with dementia, which is a research gap for the purposes of this dissertation. In discussing older adults and sexuality, however, Arien Muzacz et al. say that more research needs to be done on issues concerning sex and sexuality for older LGBTQ people in general, and I would argue that people with dementia ought to be included.³⁹ Given the social oppression that is often experienced by racial minorities, LGBTQ people, and persons with dementia, it is possible that people who are members of any and/or all of these groups may be more vulnerable to experiencing sexually oppressive circumstances and/or to making non-autonomous sexual decisions from the perspective of strong substantive accounts; they may adapt their sexual preferences on the basis of their social circumstances and available sexual options.

³⁷ It is important to note that this challenge of making autonomous sexual decisions will not necessarily apply to all people who identify under the category of "woman", but specifically "women who follow the submissive sexual script [since they] are fearful of being too sexually assertive, are unable to ask for what they desire, or believe that sexual activity is tied to their partner's arousal and orgasm, not their own." (Sanchez, Kiefer, and Ybarra, "Sexual Submissiveness in Women: Costs for Sexual Autonomy and Arousal").

³⁸ Teunis, "Sexual objectification and the construction of whiteness in the gay male community."

³⁹ Arien K. Muzacz and Adeyinka M. Akinsulure-Smith, "Older Adults and Sexuality: Implications for Counseling Ethnic and Sexual Minority Clients," *Journal of Mental Health Counseling* 35, no. 1 (2013): 11; Antonette M. Zeiss and Julia Kasl-Godley, "Sexuality in older adults' relationships," *Generations*. 25, no. 2 (2001): 18-25.

Each theory of relational autonomy has requirements about what it means to make autonomous decisions; these requirements may lead to a conclusion that some people with certain cognitive impairments, such as dementia, are non-autonomous. While this conclusion is not necessarily a problem with the theories of relational autonomy themselves, it is a problem for those who are regarded as non-autonomous as a consequence of the theories. Since autonomous decision-making is valued in our society, it is possible that people who are unable to make autonomous decisions in accordance with relational accounts may be treated differently, and perhaps unjustly, in comparison to people who can make autonomous decisions from relational autonomy perspectives. Furthermore, it may be possible for people with dementia to make autonomous decisions in other kinds of ways. For example, in order for people both with and without disabilities to be considered autonomous, disability scholars have recently started to develop novel interpretations of relational autonomy and supported decision-making; this is the type of decision-making that may be helpful for people with dementia when it comes to enabling autonomous decisions. Supported decision-making is compatible with the concept of relational autonomy since it considers a person's relationships as relevant to decision-making.

In the next two sections I illustrate two accounts of supported decision-making that may enable people with dementia to make autonomous decisions with support. The first account specifically focuses on people with dementia and sexual decision-making and the second approach considers supported decision-making for people with intellectual disabilities more broadly. Both of these approaches are a helpful step forward when it comes to recognizing people with dementia as autonomous, but there are a few potential problems to be considered. At the end of this chapter I aim to address some of these problems by proposing a more specific

framework of supported decision-making for people with dementia when it comes to sexual decision-making.

3- Autonomy, Sex, and Dementia: Boni-Saenz's Cognition-Plus Framework

In “Sexuality and Incapacity” Alexander Boni-Saenz considers whether a person with dementia who cannot consent to sex in accordance with conventional standards (namely, via one of the approaches mentioned in Chapter One) may be capable of consenting through a supported decision-making approach. Boni-Saenz is a legal scholar who is primarily concerned with the possibility of enabling people with dementia to *legally* consent to sex. He thinks that there may be cases when people with dementia are able to meet the legal requirements of what it means to consent even though additional support may be required. Let's consider some of the ethical aspects of Boni-Saenz's proposal in terms of its connection to autonomy.

Boni-Saenz's framework is based on the importance of autonomy and sexuality. As such, he tries to enable autonomous sexual decision-making *with support* for people who require assistance. He considers supported decision-making as a way to enable people with persistent cognitive impairments (e.g. dementia) to communicate their consent. Supported decision-making is ultimately when a person makes a decision with the direct support of others. There are different definitions of supported decision-making, and Boni-Saenz refers in particular to Nina A. Kohn et al.'s definition. Kohn et al. define supported decision-making as circumstances when “an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret

the individual's words and behavior to determine his or her preferences.”⁴⁰ This conception of supported decision-making shows how it differs from relational accounts of autonomy.

Supported decision-making includes the *direct involvement* of individuals who are in some kind of relation to the person making a decision, whereas relational autonomy is based on the idea that a person's autonomy will be influenced by their social context in a less direct way. Although supported decision-making and relational autonomy are different, Boni-Saenz says that supported decision-making is “a recognition and exercise of relational autonomy.”⁴¹ If we accept that relational autonomy is the most apt perspective from which sexually autonomous acts should be considered (i.e., reject Kant's self-sufficiency view), then supported decision-making will be easily compatible with sexual acts as well.

In order to show how people with dementia might be able to make autonomous decisions through supported decision-making, Boni-Saenz develops a framework called “cognition-plus”. His framework stems from “a joint focus on the mental capacities of the subject (cognition) and the recognition that some individuals achieve sexual decision-making capacity through the assistance of a decision-making support network (plus).”⁴² His cognition-plus framework involves three steps. The first step is to determine whether a person with dementia has the capacity to express a sexual volition. A sexual volition may be expressed verbally (e.g. by saying “yes” to sex) or in non-verbal ways. Some of the non-verbal ways that a sexual volition can be expressed include initiating sexual activities, displaying certain facial expressions, etc. If a person has the capacity to express a sexual volition then they are considered to be a sexual agent

⁴⁰Alexander A. Boni-Saenz, “Sexuality and Incapacity,” *Ohio State Law Journal* 76, no. 6 (2015): 9; Nina A. Kohn, Jeremy A. Blumenthal, and Amy T. Campbell, “Supported Decision-Making: A Viable Alternative to Guardianship?,” *Penn State Law Review*, 117, no. 4 (2013): 1111-1157.

⁴¹ Boni-Saenz, “Sexuality and Incapacity,” 1209.

⁴² Boni-Saenz, “Sexuality and Incapacity,” 1210.

who is potentially capable of consenting to sex; having the capacity to verbally or non-verbally express a positive interest to engage in sex is similar to what Anderson's and Pineau's models of affirmative consent would require as a foundational capacity, as discussed in Chapter One. If a person does *not* have the capacity to express a sexual volition, however, then they cannot be seen as capable of consenting.⁴³ This type of person with dementia would be excluded from Boni-Saenz's account since his account does not see them as interested in sexual acts. If the first step of Boni-Saenz's cognition-plus model is met, however, then the second step can be pursued.

The second step of Boni-Saenz's model is to determine if a person with dementia has the mental capacity to understand and reflect on the nature and potential consequences of a sexual decision (e.g. the potential to acquire sexually transmitted infections). As described in recent news, the rates of sexual transmitted infections (STIs) are increasing amongst the elderly. While further education is needed in order to reduce these rates, many people with dementia may be unable to comprehend the information and take this potential consequence of sex into account.⁴⁴ If a person *does* have the capacity to understand the nature and potential consequences of a sexual decision, then Boni-Saenz says that they can proceed to engage in sexual acts— a third party does not need to be involved to consent on the person's behalf or offer support. If a person with dementia cannot understand the possible consequences of a sexual activity, however, then a third step needs to be pursued.

The third step of Boni-Saenz's account is to assess whether an adequate decision-making support network exists for the person with dementia and for this support network to facilitate the person's wishes and desires. A support network is adequate if "it is free from conflicts of

⁴³ Boni-Saenz, "Sexuality and Incapacity," 1211.

⁴⁴ Derrick Y. McDaniel, "Sex and Seniors - STDs A New Reality For The Elderly," *Huffington Post*, April 6, 2017, http://www.huffingtonpost.com/derrick-y-mcdaniel/sex-and-seniors-stds-a-ne_b_9619778.html.

interest, has adequate knowledge of the individual and the sexual decision, and has taken reasonable steps to protect the individual... from the threat of sexually transmitted diseases.”⁴⁵ If the person with dementia has an adequate support network then they would, according to Boni-Saenz, possess the capacity to consent to sex.

Boni-Saenz’s cognition-plus framework may be helpful for many persons with dementia who are considered to be non-autonomous and unable to consent to sex in conventional ways. However, there are some possible problems with the framework, one of which relates to the third step. According to the third step, an adequate decision-making support network needs to be involved if a person with dementia is unable to independently consent to sex. A support network must be loyal to the person with dementia and free from any conflicts of interest. Some of the people who may have conflicting interests may be close family members and friends, however, which could be interpreted to mean that they should not be involved in their loved one’s sexual decision-making process; Boni-Saenz recognizes this interpretation as a problem since some of these people may actually be compatible with promoting autonomous sexual decision-making.⁴⁶ For instance, in certain circumstances a person’s prior sexual partner (namely, their sexual partner prior to their dementia diagnosis) may be able to offer decision-making support even though there is a clear conflict of interest since they have an obvious stake in the decision; the person with dementia’s sexual preferences may be most accurately interpreted by this individual. There may be some problems with sexual partners acting as a primary support person in some contexts, but insofar as the overall goal is to promote autonomous sexual decision-making then this possibility may be helpful to consider, specifically if a prior sexual partner is loyal to the person with dementia.

⁴⁵ Boni-Saenz, “Sexuality and Incapacity,” 10.

⁴⁶ Boni-Saenz, “Sexuality and Incapacity,” 12.

Another potential problem with Boni-Saenz's cognition-plus framework is in his first step, which says that people must be capable of expressing sexual volition either verbally or non-verbally in order to move forward in sexual decision-making. While non-verbal methods of communication might be frequently used for people with dementia who cannot verbally articulate their sexual desires, there are some complex challenges associated with non-verbal approaches. For instance, according to Boni-Saenz, one of the non-verbal approaches that could be used to gauge whether someone wants to have sex is that of facial expressions. While facial expressions may be helpful in certain circumstances, there are no clear facial expressions that can be seen as necessarily equating to any particular affect. Due to this lack of clarity, the potential for undue harm may be quite high. Can a smile (or any other facial expression) indicate whether a person with dementia wants to engage in a sexual act? Moreover, how could this be accurately gauged by someone who is not intimately close to the person with dementia? If, on the basis of their facial expression(s), someone pursues sex with a person with dementia, but if sexual activities are not what the person with dementia *actually* wants/if they do not understand the activity to which they seemingly want, then this could result in harm. In order to avoid this potential for undue harm, more concrete methods may be required in order to determine a person's interest in sex.⁴⁷

People with dementia can also communicate a non-verbal sexual volition on the cognition-plus framework by initiating sexual activities. According to Boni-Saenz's approach, if a person initiates a sexual activity then they could be interpreted as interested in having sex. However, this suggestion may be limiting for some sub-groups of the dementia population. One specific group that I am thinking of is some women with dementia. In her discussion of new

⁴⁷ Schulhofer, *Unwanted Sex*.

scientific information related to sex and sexuality, Emily Nagoski says that many women have a responsive sexual desire rather than a spontaneous sexual desire. A responsive sexual desire is when one's desire to engage in sex is awakened *during* a sexual act.⁴⁸ If a person develops a desire to engage in sex after their partner pursues them and they engage in a sexual activity, then they may have a responsive sexuality. Contrarily, a spontaneous sexual desire is when a person has a desire to engage in sex without being pursued by anyone else. As it turns out, women often have a responsive sexual desire, and, consequently, they may not initiate sexual activities. Although some women may have a spontaneous sexual desire, those who have a responsive sexual desire may *want* to engage in sex, but they may not experience this desire until they are pursued. If a woman with dementia does not initiate sex because she has a responsive sexual desire, then according to the cognition-plus framework, there may be some reason to question whether she has a sexual volition according to this non-verbal communication tool. The scope of the cognition-plus framework and its conceptualization of sexual agency does not consider women with responsive sexual desires.

Overall, Boni-Saenz's cognition-plus framework provides one possible way for people with dementia to autonomously consent to sexual acts with support. The framework is more inclusive than traditional accounts of relational autonomy and it responds to some of the specific needs of people with dementia; there are some potential problems to be considered, however, based on the complexities involved in sexual decision-making in certain circumstances.

⁴⁸ Emily Nagoski, *Come as You Are: The Surprising New Science that Will Transform Your Sex Life* (New York: Simon and Schuster Paperbacks, 2015), 227 and 307.

4- *Davy's Inclusive Design Approach to Relational Autonomy*

Laura Davy's inclusive design approach to autonomy provides another potential way to respond to people with dementia when it comes to sexual decision-making with support. Similar to Boni-Saenz, Davy's account responds to some of the problems that may occur for people with cognitive impairments who are seen as non-autonomous from the perspective of most relational autonomy accounts; she says that all people with intellectual disabilities have the capacity to be autonomous if they are supported by others in the right way. Davy's inclusive design approach stems from "the built environment concept of 'inclusive design' [or, universal design] and its emphasis on creating accessible environments for all persons regardless of ability."⁴⁹ Although Davy's account focuses on people with intellectual disabilities, it is pertinent to people with other cognitive impairments, such as people with dementia.

In discussing the concept of autonomy, Davy says that all people can be autonomous because autonomy can be "manifested through relations of support, advocacy, and enablement."⁵⁰ Similar to most philosophers who support relational autonomy accounts, Davy thinks that social contexts are relevant to autonomous decision-making. However, she goes a step further than traditional accounts by suggesting that people within social contexts can purposely help others be autonomous; this is similar to Boni-Saenz's concept of supported decision-making. According to Davy, support systems can help people "make [autonomous] decisions for themselves, but not necessarily on their own."⁵¹ Davy does not discuss any

⁴⁹ Laura Davy, "Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory," *Hypatia* 30, no. 1 (Winter 2015): 1.

⁵⁰ Davy, "Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory," 1.

⁵¹ Davy, "Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory," 9.

differences between different types of decisions and so her account would probably recognize people as capable of making autonomous sexual choices in the same way as non-sexual ones.

Here is one example of how Davy's approach would operate in practice. Suppose a person with dementia requires the help of a personal support worker (PSW) to complete daily activities, and the person's family plans to hire someone to meet this need. In order for the person with dementia to contribute to the hiring process, their close family members and friends could help to interpret their verbal and non-verbal cues. If the person expresses an interest in working with a particular PSW, then their family could respect their autonomous choice by hiring the PSW of their choice. By providing active support and guidance, a person with dementia can have their autonomous decisions understood and honoured.

Davy's view of autonomy shares some similarities to other theorists who have discussed supported decision-making approaches for people with cognitive impairments. For instance, in his discussion of people with autism, David DeVidi says that people with autism can be autonomous in the same way as people without autism as long as they are supported by others.⁵² The idea that people with dementia can and should be supported by others is also compatible with a conception of partnership that is proposed by Dupuis et al.⁵³ In their discussion of partnerships in dementia care, Dupuis et al. define an authentic partnership as a relationship that "actively incorporates and values diverse perspectives and includes *all* key stakeholder voices

⁵² David DeVidi, "Advocacy, Autism and Autonomy," in *The Philosophy of Autism*, ed. Jami Anderson and Simon Cushing (Maryland: Rowman and Littlefield, 2013), 187-200.

⁵³ Sherry L. Dupuis et al., "Moving beyond "patient" and "client" approaches: Mobilising 'authentic partnerships' in dementia care, support and services," *Dementia: The International Journal of Social Research and Practice* 11, no. 4 (2011): 428-450; Mitchell, Dupuis, and Kontos, "Dementia Discourse: From Imposed Suffering to Knowing Other-Wise."

directly in decision-making. It involves working *with* others, not *for* others.”⁵⁴ The authors suggest that people with dementia should be involved in decision-making processes that will influence their lives. They say that people with dementia are often able to participate if provided with the right kind of opportunity. Furthermore, one requirement of Davy’s approach is that the people involved in a decision-making process need to be deeply familiar with the person making a decision in order to accurately interpret and enable their autonomy. This requirement shares some similarities to Leslie Frances and Anita Silvers’s conception of trusteeship. In their discussion of decision-making and people with cognitive impairments, Frances and Silvers suggest that people with cognitive impairments can make autonomous decisions with the guidance of a trustee.⁵⁵ A trustee is a person who is responsible for interpreting and communicating a person’s autonomous decision(s) if they are unable to make autonomous decisions without support. While Davy does not use the language of trusteeship, one interpretation of her account could be that someone in the role of a trustee would be needed in order to enable autonomous decisions in the right way.

5- An Alternative Approach to Supported Decision-Making for Sexual Decisions

I agree with Boni-Saenz and Davy that a supported decision-making approach can help to enable autonomous decisions for people with dementia. Moreover, involving a support network that is close to the person with dementia may help to encourage a more accurate interpretation of the person’s preferences. It is important to note, however, that sexual decision-making is

⁵⁴ Dupuis et al., “Moving beyond “patient” and “client” approaches: Mobilising ‘authentic partnerships’ in dementia care, support and services,” 436.

⁵⁵ Leslie P. Frances and Anita Silvers, “Thinking About the Good: Reconfiguring Liberal Metaphysics (or Not) for People with Cognitive Disabilities,” in *Cognitive Disability and its Challenge to Moral Philosophy*, ed. Eva Feder Kittay and Licia Carlson (Massachusetts: Blackwell Publishing Ltd, 2010), 238.

importantly distinct from non-sexual decisions, and both Boni-Saenz's and Davy's theories may be inadequate from the perspective of enabling autonomous sexual decisions in the right way. It is rarely the case in Western societies that people speak openly about their sexual preferences with anyone other than their sexual partner(s). So, while family members and friends might be able to support many types of decisions for people with dementia, sexual decision-making poses a distinct challenge. An anecdote of this challenge was recently offered to me by a bioethicist, who, when given the opportunity to teach about sex and dementia, commenced the class by asking students if they were aware of their mothers' favourite sex positions. Unsurprisingly, the answer was "no". The purpose of offering this anecdote is to show that sexual preferences are rarely, if ever, discussed amongst the individuals who are typically responsible for supporting another's decisions. It is often the case that a person's sexual partner may be the only person who can comment on this type of decision-making with any certainty and/or comfort.

Both Boni-Saenz and Davy suggest that a support network of family and friends (alongside others, perhaps) can be involved in enabling autonomous decisions. However, the scope of a support network may need to be narrowed for people who had a loyal sexual partner(s) prior to their dementia diagnosis who is willing and able to support their autonomous sexual decisions. If a person had a sexual partner prior to their dementia who can interpret their decision to engage (or to not engage) in sex, then perhaps only they should be included in the sexual decision-making process; this may increase the likelihood of accurately interpreting the person with dementia and their sexual interests, especially if their interests are expressed in less explicit ways. For instance, in his discussion of sexual consent and dementia, Boni-Saenz discusses the case of Henry Rayhons. Boni-Saenz says that during the trial, Henry said that

Donna (his wife) would initiate sex by asking, “Shall we play a little bit?”⁵⁶ Although Donna did not explicitly say “I want to have sex” to communicate her sexual desire, and while other people may have been unwilling and/or unable to interpret her intent to participate in sex, her question was indicative of precisely that. In this case, only Henry may have been able to support and interpret his wife’s autonomous decision to have sex through a supportive decision-making process.⁵⁷

This kind of supported decision-making may be especially helpful when it comes to less traditional sexual activities (e.g. BDSM). Non-traditional sexual practices encounter an increased amount of stigmatization and judgment in comparison to traditional sexual practices. The potential effect that stigma may have on a support network and, ultimately, on a person’s decision to engage in sexual acts is important to consider to ensure that autonomous decisions are *actually* enabled (and that the person with dementia is not unduly influenced to make a decision based on their support network’s biases). If a person with dementia used to engage in less traditional kinds of sexual acts with a sexual partner, then their partner may be able to discuss these options with the person with dementia and accurately interpret their wishes. Other people may be unwilling and/or unable to provide the right kind of decision-making support for less traditional sexual practices, especially if they hold conflicting views about whether certain kinds of sex are ethically licit.

Although a person’s prior sexual partner would be the most likely individual to enable autonomous sexual decision-making, an accurate interpretation of a person’s sexual desires is, of

⁵⁶ Boni-Saenz, “Sexuality and Incapacity,” 16; Carole Archibald, “Sexuality and Dementia: The Role Dementia Plays When Sexual Expression Becomes a Component of Residential Care Work,” *Alzheimer’s Care Today* 4, no. 2 (April-June 2003).

⁵⁷ Michael Plaxton, *Implied Consent and Sexual Assault: Intimate Relationships, Autonomy, and Voice* (Montreal: McGill-Queen’s University Press, 2015).

course, not guaranteed; there are a few reasons that a process of supported sexual decision-making could encounter challenges irrespective of the support network involved. First, if the support network is a prior sexual partner then it may result in a conflict of interest and an increased likelihood of intentional or unintentional exploitation. A person's partner might say that they want to enable the person's sexual autonomy and are capable of doing so, but they may, in fact, not be a person whose assessment of the situation should be authoritative. The reason for this challenge is because the support network will gain something if the decision goes one way rather than another. Second, there is the possibility of any support network projecting their own sexual preferences onto a person with dementia, even if such projections are unintentional. Imposing one's values onto another person defeats the purpose of enabling autonomous sexual decisions or supported decision-making through a relational approach since any decisions will not accurately reflect the appropriate person (namely, the person with dementia). If values are imposed onto a person with dementia then any corresponding decisions may fall under a framework of shared agency instead of relational autonomy or supported decision-making. Third, dementia can cause personality and behavioural changes, and it is possible that a behaviour that previously meant "yes" to sex may no longer mean the same thing; a person might communicate agreements/disagreements differently if they experience personality and behavioural changes. One reason that someone with dementia may communicate differently when it comes to sex and/or express a stronger desire to engage in sex may be because of symptoms such as hypersexuality, which we discussed in Chapter One. Although it is a relatively uncommon symptom, hypersexual behaviors may have the potential to skew conceptions about whether a person with dementia is making an autonomous sexual choice, even with support.

Finally, there may be cases when someone does not have a past sexual partner and in this kind of case it may be less clear how to proceed.

Based on the possibility that a person with dementia may not be supported in the right way, even when they are supported by a past sexual partner, I want to go one step further in proposing a new way to think about supported decision-making for sexual decisions. One way to mitigate some of the potential challenges of supported sexual decision-making for people with dementia could be by using part of an approach described by James Lindemann Nelson. In “Alzheimer’s Disease and Socially Extended Mentation”, Nelson discusses semantic externalism, which is a theory in the philosophy of mind. He says that the view “brings with it a suggestion that our relationship to our own mental contents—and therefore, in an important sense, to ourselves—is not immediate but travels through various social arrangements”⁵⁸; a person’s self and their values and decisions may change based on their circumstances. Nelson considers situations where people with dementia may hold new views or desires that are inconsistent with previous beliefs. In response to these kinds of conflicts, Nelson seems to suggest that the new views will need to be carefully judged in comparison to prior beliefs (which are inconsistent with the new ones). From a perspective of autonomy and supported decision-making, however, I suggest that if a person’s *new* views/desires are consistent with other *present* beliefs, then this may help us to determine whether the decision could be seen as autonomous. Let’s suppose that a person with dementia expresses new values and desires in comparison to those expressed by their pre-dementia self. In response to this kind of scenario, I suggest that one way to determine whether their values and expressed preferences ought to be respected, and

⁵⁸ James Lindemann Nelson, “Alzheimer’s Disease and Socially Extended Mentation,” in *Cognitive Disability and its Challenge to Moral Philosophy*, ed. Eva Feder Kittay and Licia Carlson (Massachusetts: Blackwell Publishing Ltd, 2010), 227-228.

whether they are autonomous, would be based on whether they are *consistent* in the present moment. For instance, if a person with dementia values sexual monogamy in accordance with their pre-dementia self while at the same time valuing polyamory, then any promiscuous sexual behaviors in accordance with their polyamorous desires may not be deserving of respect from the perspective of autonomy; they would not be seen as autonomous because of this inconsistency. However, if a person with dementia expresses sexual interests that are compatible with other present values and consistently communicated, then perhaps they ought to be considered autonomous and respected accordingly. According to this framework, if a person with dementia receives decision-making support from a past sexual partner or from another caregiver (if there is no past partner), and if they consistently express a particular sexual preference or value that accords with other values and preferences, then the sexual preference would be seen as autonomous. The reason for adding this point about consistency is in order to ensure that a person with dementia is, in fact, making an autonomous decision with support and is not unduly influenced by and/or misinterpreted by others⁵⁹; if a consistent decision is expressed over a period of time and if it accords with other values and decisions, then we may be able to more confidently assert that a person is making an autonomous choice. Consistency is especially important since people with dementia are a vulnerable population whose decision-making capacities and moments of lucidity will fluctuate. We can consider one of the examples discussed in Chapter Two to show how this modified supported decision-making framework might work.

In Chapter Two, I presented a case that involved two gay men with dementia having sex. These individuals were not sexual partners prior to their dementia diagnoses. Upon witnessing

⁵⁹ For instance, in Henry Rayhons's case, Donna's daughters, her nursing home caregivers, and Henry disagreed about whether Donna had the capacity to consent to sex and wanted to participate (Boni-Saenz, "Sexuality and Incapacity," 17). Consistency may help to mitigate these kinds of conflicting interpretations.

this interaction, a nursing assistant forcibly removed the two men from one another and one of the men was required to move to another facility. Now, let's suppose that the motivation for separating these two men was because the nursing assistant did not think that they were making autonomous choices. If we apply the above approach to this particular case, then the nursing assistant could have determined whether the men were making autonomous sexual decisions based on whether they were able to make decisions with support and if their decisions were consistently expressed over a certain period of time. If the men were constantly in one another's rooms, undressing in front of one another, explicitly stating that they wanted to have sex with one another, etc., then their decisions to have sex with one another might be considered autonomous. If, however, one of the men *also* expressed a desire to refrain from sexual activities and/or passionately expressed that they wanted to have sex with their wife, then their decision to engage in sex may not be considered autonomous. This would be problematic from the perspective of autonomy.

Overall, both Davy's and Boni-Saenz's accounts of supported decision-making encourage people with dementia to be supported by individuals who are close to them. When it comes to sexual decision-making, however, I suggest that perhaps only past sexual partners, when available, should be involved in decision-making processes since other family members and friends may be unable to (or, at least, less easily able to) appropriately gauge and interpret a person's sexual preferences. Although it may be preferable for a past sexual partner to support autonomous sexual decision-making, a concern about how to mitigate potential harms and to appropriately gauge autonomous decisions irrespective of the support network remains present. In order to ensure that a process of supported decision-making occurs in the right way and that

people with dementia are making autonomous choices, I suggested that a person's expressed sexual preferences should be consistent and compatible with other present values and decisions.

6- Additional Challenges of Relational Autonomy

The above framework is a type of supported decision-making that is based on a conception of relational autonomy. Although this approach may be a helpful step forward in enabling autonomous sexual decisions, there are some problems that would need to be considered if this framework were translated to practice. One problem is that the above framework, which stems from the other approaches explored in this chapter, does not specifically consider some of the intersectional challenges that may exist for people with dementia who are members of certain groups, and it is unclear how this can be done. For instance, there may be no way for a support network to know if a woman with dementia is autonomously agreeing to maintain a submissive role in sex or whether it is an adaptive preference because of the way that she was socialized to behave and the limited set of options that are seemingly available. If adaptive preferences are non-autonomous then this is problematic, and none of the approaches above consider the possibility and complexity of people saying "yes" to sex but perhaps for the wrong reason(s). Similarly, people who are members of historically oppressed groups may be silenced in ways that other groups are not, such as LGBTQ people. These potential inequities are relevant to exploring the ethics of sexual acts, but they are not specifically addressed.⁶⁰

Another possible problem relates to the complexities that may occur if people with dementia want to engage in activities to which they were previously opposed, especially if a person's prior sexual values were crucial to their identity. For instance, suppose a person with

⁶⁰ At least insofar as justice and equity are ethically relevant factors.

dementia wants to have sex with someone other than their pre-dementia sexual partner. In this kind of case, my proposed framework would entail that the factor to consider is whether the person is making an autonomous choice with appropriate guidance and support in the current context, but there may be cases when past sexual values are seemingly more significant. To see what I mean, consider as an example a former nun who valued the idea of maintaining a life of chastity. In this kind of scenario, the significance of this person's prior sexual values in relation to their sense of self, identity, and dignity may be important to consider.⁶¹ Some of these considerations will be discussed in the next chapter and in Chapter Six.

A third problem to consider when it comes to relational autonomy and sexual acts for people with dementia stems from the common stereotype that people with dementia are and should be non-sexual. This stereotype has existed for a long time for people with cognitive impairments, such as the case in which “mentally defective” men and women were segregated in psychiatric institutions in order to prevent sexual relations from occurring.⁶² This stereotype continues to exist, where our “society is generally uncomfortable with the notion that people who are ill or disabled might still want to have sex.”⁶³ The unwillingness to recognize that people

⁶¹ Andrea Lavazza and Massimo Reichlin, “Of meatballs, autonomy, and human dignity: Neuroethics and the boundaries of decision-making among persons with dementia,” *American Journal of Bioethics Neuroscience* 9, no. 2 (2018); in their discussion about whether to value a person with dementia's current preferences even if they conflict with past preferences, Lavazza and Reichlin discuss the relevance of dignity. Maintaining a person's dignity may be a reason for a person's past preferences to be followed.

⁶² Winnie Hu, “Too Old for Sex? Not at This Nursing Home,” *The New York Times*, July 12, 2016, <https://www.nytimes.com/2016/07/13/nyregion/too-old-for-sex-not-at-this-nursing-home.html>; Licia Carlson, *The Faces of Intellectual Disability: Philosophical Reflections* (Bloomington: Indiana University Press, 2010), 59; Cort, Attenborough, and Watson, “An initial exploration of community mental health nurses' attitudes to and experience of sexuality-related issues in their work with people experiencing mental health problems”; Chris Quinn and Graeme Browne, “Sexuality of People Living with a Mental Illness: A Collaborative Challenge for Mental Health Nurses,” *International Journal of Mental Health Nursing* 18 (2009): 195–203. doi: <https://doi.org/10.1111/j.1447-0349.2009.00598.x>2009; Quinn, Happell, and Browne, “Talking or avoiding? Mental health nurses' views about discussing sexual health with consumers,”; Perlin & Lynch, *Sexuality, Disability, and the Law: Beyond the Law Frontier?*

⁶³ Quinn and Browne, “Sexuality of People Living with a Mental Illness: A Collaborative Challenge for Mental Health Nurses,” 196.

with dementia may want to have sex is problematic for relational accounts in general. If a person with dementia is seen as non-sexual then the idea of guiding them to make an autonomous sexual choice may be moot. In order to combat this stereotype, further education is needed, but insofar as these perceptions continue to exist then supported decision-making accounts may not help when it comes to enabling autonomous sexual decisions.

7- Conclusions

The purpose of this chapter was to consider whether people with dementia can autonomously consent to sex through a framework of relational autonomy and supported decision-making. Relational autonomy accounts suggest that people can be autonomous while at the same time being influenced by social contexts. Furthermore, theories of relational autonomy recognize that oppressive social constructs have the potential to influence and inhibit autonomy, which may be relevant to some people with dementia. Supported decision-making is a more specific way to enable people with dementia to make relationally autonomous decisions.

Although theories of relational autonomy are meant to expand the scope of people who are seen as autonomous (e.g. women), I argued in this chapter (and in previous work⁶⁴) that some people with certain cognitive impairments are still seen as non-autonomous. This is problematic given the importance of autonomy and its relevance to sexual decisions. In response to this problem, I considered two other approaches to autonomous sexual decision-making for people with dementia. Boni-Saenz's cognition-plus framework was the first approach explored in this chapter and Davy's inclusive design approach was the second approach.

⁶⁴ Bianchi, "Sexuality, Autonomy, and Intellectual Disability."

One possible challenge with Davy's and Boni-Saenz's accounts is that they do not adequately consider some of the additional complexities that may be relevant to the sexual domain. Sexual decision-making is importantly distinct in comparison to other activities—it is often a taboo topic that a typical support network (e.g. family members and friends) may be unable to support. In order to ensure that people with dementia are supported to make autonomous sexual decisions in the right way, I suggested that only past sexual partners should be involved in supporting a person with dementia's sexual decisions if a loyal past sexual partner exists. Beyond this, however, I suggested that people with dementia should only be considered to be making autonomous sexual choices if their expressed sexual preferences are consistent with other values and beliefs (both sexual and non-sexual), irrespective of the support network involved. A consistent expression of preferences, values, and beliefs may help to mitigate the potential for misinterpretations and value impositions when it comes to sexual acts.

The final part of this chapter highlighted some additional problems to consider for relational autonomy and supported sexual decision-making, such as the relevance of prior sexual values. In response to this challenge, I will introduce an approach that considers prior autonomous decisions in the next chapter.

Chapter 4

A Framework of Advance Sexual Consent

In Chapter Three I considered a framework of relational autonomy and supported decision-making as a way to enable people with dementia to autonomously consent to sex. In this chapter I consider another framework of consent for people with dementia, namely, advance sexual consent. According to this framework, people with dementia would be seen as consenting to sex based on prior autonomous sexual decisions as communicated in advance directives.

The framework of advance consent that I introduce in this chapter expands on what is typically used in the medical domain in relation to advance medical directives, where people can make autonomous medical decisions (or, at least, highly influence the medical decisions that are made on their behalf) prior to becoming incapable.¹ Using a framework of advance consent has not been thoroughly considered for the sexual domain and specifically for people who cannot consent in conventional ways. As of now, if someone consents to sex on one occasion then their consent cannot be transferred to a future point in time—a person's consent is only valid at the time of a sexual act. The law against advance sexual consent was motivated by the case of *R. v. J.A.*, which is when the Supreme Court of Canada decided that it is illegal to have sex with someone who is unconscious even if they previously consented. I explain this case below. In this chapter, I consider the idea that some people with dementia could potentially consent to sex through a framework of advance sexual consent and that this practice may be ethically licit from the perspective of autonomy.

¹ John K. Davis, "Precedent Autonomy, Advance Directives, and End-of-life Care," in *The Oxford Handbook of Bioethics*, ed. Bonnie Steinbock (New York: Oxford University Press, 2007); Marcia Ann Sokolowski, "An Examination of the Moral Authority of Use of Advance Directives with the Alzheimer's Dementia Population" (doctoral thesis, University of Waterloo, 2010): 1; Sokolowski notes that advance directives are sometimes referred to as living wills or directives.

In the first part of this chapter I describe the idea of advance directives as applied to sex (which will be referred to as advance sexual directives) and compare this framework to advance medical directives. Advance sexual directives would apply to people who are incapable of consenting to sex in typical ways for an indefinite period of time, such as people with dementia. Next, I introduce some general arguments in support of advance directives and in opposition to advance directives and consider how these arguments may apply to the idea of advance sexual directives. The arguments in support of and against advance directives are polarized. In order to merge the gap between these polarized views, I introduce Boni-Saenz's "consensus of consents" model of sexual consent; this is a different proposal than the one introduced in the preceding chapter. Boni-Saenz's model may be a way for people with dementia to consent to sex if they are unable to consent in conventional ways; his model is especially pertinent to people who can express an explicit willingness to participate. I expand on Boni-Saenz's view so that people can have their advance sexual directives and current decisions considered even if they cannot explicitly and affirmatively consent to sex at the present time; this is referred to as a hybrid framework. I will conclude this chapter by highlighting some potential benefits and challenges with this framework of advance sexual consent.

There is one assumption that I want to elucidate prior to introducing and considering a framework of advance sexual consent. It seems that advance sexual consent could be justified by using a principle of precedent autonomy. Precedent autonomy is essentially when prior autonomous decisions are considered to be presently relevant (specifically when the person to whom they apply is incapable of making an autonomous choice). This concept will be thoroughly explained below. While the significance of precedent autonomy and autonomous decision-making might seem to suggest that I need to endorse a particular view of what it means

to make an autonomous choice, I will not be taking a stand on this complex debate. What I say in this chapter is meant to apply to whatever theory of autonomy one supports.

1- Advance Sexual Directives

As mentioned in Chapter One, consent is an essential part of engaging in sexual acts, and consent must be offered at the time of a sexual occurrence. If a person says “yes” to sex on one occasion, then their consent is only applicable to that circumstance; a person cannot presume who someone wants to engage in sex with based on prior consent.

The law in Canada that prevents people from consenting to sex in advance of a sexual activity was solidified in May 2007 in the case of *R. v. J.A.* The case involved a man and a woman who often engaged in consensual kinky sex. The woman consented to erotic asphyxiation, which is when a person is choked to prevent oxygen flow and increase sexual arousal.² During one encounter, the woman was asphyxiated and she became unconscious for about three minutes. While the woman was unconscious, her partner tied “[her] arms behind her back and inserted a dildo into her anus.”³ Upon regaining consciousness, the woman consented to penile-vaginal intercourse, and then her bonds were removed when she said her safe word.⁴ Although the woman consented to being asphyxiated, her partner was later convicted of sexual assault by the Supreme Court of Canada because it was regarded as impossible for someone to

² Alexander Boni-Saenz, “Sexual Advance Directives,” *Alabama Law Review* 68, no. 1 (2016): 2; Lisa Downing, “Beyond Safety: Erotic Asphyxiation and the Limits of SM Discourse,” in *Safe, Sane, and Consensual: Contemporary Perspectives on Sadomasochism*, ed. Darren Langdridge and Meg Barker (New York, Palgrave Macmillan, 2007), 120–21.

³ Boni-Saenz, “Sexual Advance Directives,” 2-3.

⁴ “The BDSM community requires the use of a “safe word” that, if uttered by the submissive, requires the dominant to immediately cease his or her actions.” (Margo Kaplan, “Sex-Positive Law,” *New York University Law Review* 89, no. 1 (April 2014).

offer consent in advance of a sexual act. Since the woman could not have consented to the sexual activities that occurred when she was unconscious, her partner's acts were ruled illegal.

Although the case of *R. v. J.A.* involved a person who was temporarily incapable of consenting to sexual activities because of erotic asphyxiation, the implications of the Court's decision extend beyond cases of temporary incapacity; prospective consent to sex is also prohibited for people who are incapable of consenting for a significant, often perpetual, period of time, such as people with dementia.⁵ Given that people with dementia are often unable to consent to sex, and since advance sexual consent is legally prohibited, they are essentially barred from engaging in legal sexual acts. Furthermore, if the law reflects the ethical values of a particular society at the time of its development then it appears that prospective consent to sex may be viewed as ethically illicit alongside its legal status, and at least one of the ethical principles that justifies this idea is the principle of autonomy. If a person changes their mind about engaging in a particular act then their most recent decision is the one that ought to be honoured as a matter of respecting their autonomous choice.

In response to the Court's ruling in *R. v. J.A.*, legal scholar Boni-Saenz has proposed that prospective consent to sex ought to be considered legally licit under certain circumstances. He says that there are many reasons that people might want to prospectively consent to sex. For instance, people might want to ensure that their future disabled selves lead sexually fulfilling lives, maintain certain sexual identities or relationships, and/or they might want to protect their spouse from potential sexual assault convictions (e.g. the case of Henry Rayhons). Both Canada and the United States of America have implemented laws "that recognize advance directives in a

⁵ Boni-Saenz, "Sexual Advance Directives," 3.

variety of decision-making domains,”⁶ such as in the financial and medical domains. Since prospective consent is ethically and legally licit in these areas, perhaps there might be some reason to at least consider the possibility of prospective sexual consent as well. In order to provide people with some assurance about their future sexual lives in case they lose their capacity to consent, I will explore what I am referring to as advance sexual directives.

Advance sexual directives would be used in the same way as advance medical directives, but with a specific focus on sexual decisions. In the medical domain, advance directives are used to communicate a person’s prior autonomous medical decisions (precedent autonomy). The term “advance directive” is a legally recognized concept in the United States, and while it is not a part of Canada’s legal vernacular, it is frequently used by people in the healthcare field.⁷ Consequently, I will be using the term “advance directive” in this chapter.

An advance directive is a document that “permits an individual to make decisions in advance or to delegate decision-making authority in advance of incapacity.”⁸ There are various reasons that a person might be incapable of consenting to a particular medical decision, such as intoxication, unconsciousness, a dementia diagnosis, etc. Some of these factors may temporarily inhibit one’s capacity to consent to a medical treatment (e.g. intoxication), whereas others may be more permanent (e.g. dementia). However, what is important to note is that each of these

⁶ Boni-Saenz, “Sexual Advance Directives,” 13; The United States of America’s laws are state-based. All of the states have implemented these kinds of laws.

⁷ In Canada, the term “advance care plan” is supposed to be used instead of “advance directive”. I am making my claim about the language that is used in Canadian healthcare based on my personal experiences working in the healthcare field at the time of writing this dissertation.

⁸ Boni-Saenz, “Sexual Advance Directives,” 10; The process that is used to prove that one is capable of consenting to a medical treatment is twofold: (1) one must first demonstrate that one can *understand* the treatment being proposed and; (2) one must show that one can *appreciate* that any treatment outcomes will influence oneself (and not, for instance, someone else). If a person both understands and appreciates a proposed medical treatment then they are considered to be capable of consenting. Having the capacity to consent assists individuals in being able to make autonomous decisions in the medical domain.

factors can influence one's capacity to understand and appreciate the relevant treatment(s) being proposed in a medical context. This is a problem given the significance of respecting individuals' autonomous decisions in the medical domain.

Advance directives allow people to outline the type of care that they would want to receive just in case they become incapable of consenting/refusing to consent at a future point in time. Typically, advance directives are used to indicate a person's end-of-life preferences, such as whether one wants to receive life-sustaining treatments in certain contexts. Advance directives are meant to "employ the coercive force of the law to authorize others to impose our past will on ourselves"⁹ thereby enabling people with dementia to indirectly contribute to present decisions based on former capable choices. For instance, a Jehovah's Witness who wants to ensure that they do not receive a blood transfusion could outline this decision in an advance directive. Then, if they are diagnosed with dementia (or another incapacitating illness), their advance directive would provide explicit instructions to others about what to do in case they require a transfusion and cannot consent. An advance directive allows the person with dementia to communicate their most important preferences; they are able to indirectly participate in present decision-making processes through their directive.

There are two kinds of advance directives that exist in the healthcare system: living wills and powers of attorney.¹⁰ Living wills are documents that people develop to outline their specific medical preferences just in case they become incapable of making a choice. Living wills are sometimes referred to as instructional directives since instructions are given by an individual about the type of care that they would/would not want to receive. An instructional directive can

⁹ Boni-Saenz, "Sexual Advance Directives," 20.

¹⁰ Davis, "Precedent Autonomy, Advance Directives, and End-of-life Care."

incorporate two types of instructions. The first type of instructions are *permissive*, in which people can give permission to pursue particular types of care.¹¹ For instance, a person might write an advance directive that says that they *want* to be given a tracheostomy or put on a ventilator if they are unable to make a decision and in need of a tracheostomy or a ventilator in order to survive.¹² This would be a permissive advance directive since the person gives permission to have a type of treatment under certain conditions. The second type of instructions are *restrictive*. Restrictive instructions are when a person restricts/does not give their consent to pursue certain kinds of medical interventions. For instance, a person who signs a “do not resuscitate (DNR)” order is restricting medical personnel from resuscitating them just in case they need to be resuscitated and are incapable of communicating their choice. Both types of instructions can be included in a person’s advance directive in the form of a living will.

The second type of advance directive is a proxy directive or a power of attorney. Proxy directives are used to indicate someone’s substitute decision maker, namely, someone who is authorized to make decisions on the person’s behalf just in case they become incapable of making a choice. If someone becomes incapable and a medical decision needs to be made, then a person who is the medical power of attorney would be responsible for making a decision on the person’s behalf. Sometimes living wills and proxy directives are incorporated into a hybrid or combined directive, which “designate[s] a proxy decision-maker but also provide[s] written guidance about the principal’s beliefs in varying levels of mandatory language”¹³ combining “instructional and delegational elements.”¹⁴

¹¹ Boni-Saenz, “Sexual Advance Directives,” 10 and 11.

¹² “[A] tracheostomy is an opening surgically created through the neck into the trachea (windpipe) to allow direct access to the breathing tube” (Johns Hopkins Medicine, “What is a tracheostomy?,” accessed March 25, 2018, <http://www.hopkinsmedicine.org/tracheostomy/about/what.html>).

¹³ Boni-Saenz, “Sexual Advance Directives,” 12.

In John K. Davis's discussion of precedent autonomy and advance directives, he says that living wills are the most obvious way for people to express their preferences for a future point in time. According to Davis, there is a three-tiered spectrum of autonomy that exists amongst decision-making frameworks. The three tiers are hierarchical in terms of recognizing and respecting the principle of autonomy. The first tier is when people can make their own choices in the present context and communicate their autonomous preferences. This is the most ideal framework when it comes to autonomous decision-making. When it is not possible for people to make autonomous decisions (due to factors like dementia) then living wills are the next best option since they include explicit instructions that are written by the person to whom they apply. The third best framework is powers of attorney/proxy directives. Davis says that "[a]s we move down this list, the patient's autonomous choices become less clear and more hypothetical."¹⁵

The importance of respecting a person's prior autonomous decisions through advance directives can be explained by what Davis calls the "Extension View" of the self. The idea is that "people have the same moral authority over their future affairs that they have over their current affairs—it is simply extended forward."¹⁶ For Davis, respecting autonomous choices is morally significant irrespective of when the autonomous decisions are made. So, the argument goes, that insofar as the principle of autonomy ought to be respected as a matter of respect for persons then so should the principle of precedent autonomy; advance directives provide a way for this principle to be followed. The principle of respect for persons is the idea that all people are intrinsically valuable and their preferences ought to be taken into account regardless of whether

¹⁴ T.P. Gallanis. "Write and Wrong: Rethinking the Way We Communicate Health-Care Decisions", *Connecticut Law Review* 31, no. 3 (Spring 1999), 1019.

¹⁵ Davis, "Precedent Autonomy, Advance Directives, and End-of-life Care," 5.

¹⁶ Davis, "Precedent Autonomy, Advance Directives, and End-of-life Care," 2.

they are capable of making their own decisions. Karin Rolanda Jongsma and Suzanne van de Vathorst say that “[r]espect for persons has two moral dimensions: respect for autonomy and protection of persons with diminished autonomy.”¹⁷ The first dimension applies to people who are capable of making present autonomous decisions and the second dimension is what motivates the idea that people’s prior autonomous decisions, or precedent autonomy, ought to be considered; the second dimension may include people with dementia.¹⁸

The importance of including people with dementia in their decisions and respecting the principle of precedent autonomy if they cannot make autonomous decisions is a standard procedure in most, if not all, applied contexts. As a part of this doctoral research, I completed an applied philosophy research placement at two healthcare organizations in Toronto, Ontario, Canada.¹⁹ This project involved interviewing a total of twenty-seven healthcare professionals who had experience working with people with cognitive impairments who may be unable to consent to medical decisions. A specific focus was on people with dementia. The purpose of this project was to answer two questions: (1) the descriptive question of whether people with dementia do contribute to their care and medical decisions if they cannot contribute to decision-making processes or consent in typical ways and (2) the normative questions of whether and how they ought to participate. The interviews were semi-structured, which means that a standard list

¹⁷ Karin Rolanda Jongsma and Suzanne van de Vathorst, “Beyond competence: advance directives in dementia research,” *Monash Bioethics Review* 33, (2007): 169, doi: 10.1007/s40592-015-0034-y.

¹⁸ M. Therese Lysaught, “Respect: Or, How Respect for Persons Became Respect for Autonomy,” *Journal of Medicine and Philosophy* 29, no. 6 (2004). Since people with dementia have a history of autonomy, a principle of precedent autonomy suggests that their prior autonomous choices can and should be considered at the present time; *The Belmont Report*—a report that was crafted to help guide the conduct of research involving human subjects—was the first place where the principle of respect for persons was publicized. The principle applied to people with autonomy and with diminished autonomy (e.g. people with dementia). People with diminished autonomy were meant to be protected from harm as a part of the principle of respect for persons, however, the use of this principle has expanded in practice and the decisions of people with diminished autonomy are typically considered relevant.

¹⁹ This research project was approved by the research ethics boards at both organizations and the University of Waterloo.

of questions was answered by every participant for comparative purposes, but I could follow up on responses as needed. During these interviews, almost every interviewee said that people with dementia do participate in their decisions to a certain extent.²⁰ More importantly, however, interviewees said that people with dementia *should* be empowered to participate.

Many interviewees offered suggestions about how people with dementia can and should participate in their decisions, often referring to the relevance of prior wishes and values. Having access to a person's prior wishes and values allows decision-makers and healthcare workers to determine whether a person with dementia would plausibly support the decision(s) being made if they were capable. In other words, having access to prior wishes and values allows the person with dementia to *indirectly* participate in their present decisions. The interviewees in this study commonly mentioned advance directives in the form of living wills as a way for people with dementia to contribute to decision-making processes; this reinforces Davis's hierarchy where advance directives in the form of living wills were second on the hierarchy.²¹

Although advance directives were originally developed to outline end-of-life decisions, different types of advance directives for people with dementia are now being considered; one example is advance research directives. Advance research directives are meant to outline individuals' decisions about participating in medical research projects just in case they become incapable of consenting at a future point in time.²² Typically, people need to be capable of

²⁰ I say that people with dementia contribute to their decisions *to a certain extent* because most interviewees said that there is a lot of work to be done to include people with dementia in their decisions in the right way—they have the potential to contribute, but we need to offer them opportunities and enable them to do so.

²¹ There is a practical problem with living wills that many healthcare professionals mentioned as relevant. The problem is that most people do not create advance directives in the form of living wills. This is not a criticism of the idea of living wills (which are often seen as ideal in terms of enabling autonomous decision-making for non-autonomous persons) but rather one of practicality.

²² Tom Buller, "Advance consent, critical interests and dementia research," *Journal of Medical Ethics*, 41 (2015): 701-707.

providing informed consent to participate in medical research trials. Since people with dementia may be unable to understand and/or appreciate what it means to participate in medical research trials, they are often unable to join.²³ While substitute decision makers may consent on behalf of the person with dementia, the person with dementia cannot contribute to a choice that represents their own desires and interests in a way that respects the principle of autonomy in the most effective way (since they cannot form and communicate their decisions in one of the top two ways according to Davis's hierarchy). This poses a significant problem since the principle of autonomy is important *and* including persons with dementia in medical research trials is necessary in order for medical advances to be made. Advance research directives have been proposed as a way to overcome this obstacle so that people with dementia can communicate their consent.²⁴

Similar to the above examples of advance medical directives and advance research directives, advance sexual directives would allow people to outline their willingness or unwillingness to participate in sexual activities just in case they become incapable of consenting at a future point in time because of a dementia diagnosis (or another incapacitating illness/factor). In order to show how advance sexual directives would work, consider the following:

²³ In order to be capable of consenting to research or treatment a person needs to be able to understand and appreciate the nature and potential consequences of whatever is being proposed.

²⁴ One concern with advance research directives is whether the true motivation for permitting them is, in fact, autonomy. While part of the motivation for advance research directives may be to enable autonomous decision-making and respect prior autonomous decisions, an even stronger motivation may be from the perspective of the researchers. It may be the case that a reason for permitting advanced directives has more to do with the needs of researchers being able to do research on subjects who cannot consent (and to permit something that looks like autonomous consent). The same concern would apply to advance sexual directives. While I cannot address this concern here (other than to say that my motivation for considering advance consent *is* to enable autonomy/precedent autonomy), it is a concern worth flagging.

Suppose that Martha values being in a monogamous relationship with her long-time partner. Martha is sexually deferent and almost always agrees to participate in sexual acts when her partner initiates. Martha wants to ensure that she can remain sexually intimate with her partner even if she becomes incapable of consenting in a conventional way because of a dementia diagnosis; she wants her sexual preferences and consent to extend to future circumstances. In order to ensure that her sexual decisions are known, she communicates them in an advance sexual directive, similar to the way that her future medical decisions are documented. If Martha is diagnosed with dementia then the principle of autonomy/precedent autonomy would suggest that her prior sexual wishes and values ought to be respected. Sexual acts with her partner could be judged as ethically licit from the perspective of autonomy even if she is unable to autonomously consent at the relevant time.²⁵

To take another example, suppose Aliyah was married for 10 years when her spouse unexpectedly dies. As a widow and devout Christian, Aliyah does not want to engage in any new intimate relationships or sexual activities; it is important for her to remain faithful to her late spouse. In order to ensure that she adheres to this decision just in case she is ever diagnosed with a disease like dementia, Aliyah develops an advance sexual directive. In her directive, Aliyah specifies her decision to remain celibate since the passing of her husband.

As a final example, suppose Ali has been married for many years to a person who rarely wants to have sex. Due to their minimal sexual experiences, Ali decides that if they are diagnosed with dementia, then they would want to engage in sexual activities with new partners if they are interested at the time. They do not feel that it is necessary to remain loyal to their sexually uninterested spouse.

²⁵ The possibility of someone like Martha being unresponsive or dissenting will be considered below.

One important practical point to consider about advance directives in general is that they “typically require a third party to oversee their use, such as the medical profession in the case of health care advance directives.”²⁶ The staff at long-term care facilities would likely be the ones to provide third party oversight in the case of advance sexual directives as well, especially for people with decreasing cognitive capacities (when the likelihood for being in a care home increases). In the remainder of this chapter, I consider advance sexual directives for people in these kinds of contexts (e.g. long-term care homes). Although it is possible that people with dementia may remain at home, the purpose of creating advance directives is typically so that an individual’s wishes are communicated and can be verified by third parties in other contexts. This is important to keep in mind when it comes to considering the ethics of advance sexual directives; advance directives are meant to honour precedent autonomy, but third parties may decide that a person’s prior autonomous preferences are harmful or wrong based on their own sexual values or beliefs. Balancing the principles of autonomy and non-maleficence, as well as trying to maintain a person’s dignity, can be complex when other people are involved.

2- In Support of Advance Directives

The purpose of advance sexual directives is to provide a way for people to express their autonomous sexual preferences just in case they become incapable of consenting at a future point in time. However, the question of whether advance directives enable individuals to autonomously contribute to future decisions in the right way has been a topic of philosophical debate.

²⁶ Boni-Saenz, “Sexual Advance Directives,” 15.

In his discussion on advance medical directives, Ronald Dworkin argues in support of their use.²⁷ He says that individuals have a right to make autonomous choices, and advance directives are one way for people to communicate their choices and have their autonomy respected in case they become incapable. Dworkin says that advance directives ought to be followed as a matter of respecting the principle of precedent autonomy even if a person's directive does not appear to be in their best interest(s) at the relevant time. In his defense of advance directives, Dworkin distinguishes between experiential and critical interests to explain why people want to live their lives in certain ways.

The first reason that people have preferences about how they want to live is because of *experiential interests*. Experiential interests are those that contribute to people's happiness and enjoyment.²⁸ Some examples of experiential interests might be activities such as playing video games, reading books, going for walks, etc. Although one's life would be less enjoyable if one were unable to fulfill these interests, it is not necessarily the case that one's life would be less meaningful or that one's identity would be altered without them.

The second reason that people want to live in certain ways is because of *critical interests*. Critical interests are "[c]onvictions about what helps to make a good life."²⁹ They provide one's life with meaning. An example of a critical interest might be to maintain certain religious practices if these practices bring a sense of meaning to one's life; the reason that one may want to maintain certain religious practices might *not* be because one "happen[s] to want the experience; on the contrary... a life without wanting [to pursue religious practices] would be a

²⁷ Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (New York: Alfred A. Knopf, Inc., 1993), 190-196; Boni-Saenz, "Sexual Advance Directives," 22.

²⁸ Dworkin, *Life's Dominion*, 201.

²⁹ Dworkin, *Life's Dominion*, 201-202, *supra* note 114.

much worse one.”³⁰ Boni-Saenz describes critical interests as those which are “intertwined with our values, our life plan, and our narrative sense of self.”³¹ The narrative sense of self that may apply to Dworkin’s view (and the view communicated by Boni-Saenz) is the idea that one’s life is constructed in the form of a traditional story, where all of the episodes of one’s life can be intelligibly linked together with a beginning, middle and end; this view is reinforced by Marya Schechtman’s narrative self-constitution view.³² Based on the idea that we constitute ourselves as persons on the basis of autobiographical narratives, Schechtman says “[t]he fact that persons experience their lives as unified wholes makes it rational for a person to have a special kind of concern for her own future.”³³ The narrative self-constitution view is compatible with Dworkin’s idea that a person may have a special concern for their future because of their critical interests (which continue to represent them as a unified whole). While Dworkin does not refer to a narrative view of the self, it is a pertinent view to consider since Dworkin *does* say that critical interests continue to exist irrespective of one’s recognition of them. Similarly, Schechtman suggests that if a person with dementia is unable to self-narrate their lives from a first-person perspective then their friends and family can continue their narrative by respecting their prior autonomous decisions. If one’s critical interests continue to exist without one’s recognition of them, then this may be because they are part of one’s overall narrative or story.

Dworkin says that advance directives are important to follow because they incorporate critical interests. Critical interests reflect an individual’s desire to die under certain

³⁰ Dworkin, *Life’s Dominion*, 202.

³¹ Boni-Saenz, “Sexual Advance Directives,” 23.

³² Marya Schechtman, *The Constitution of Selves* (Ithaca, Cornell University, 1996), 105; Boni-Saenz, “Sexual Advance Directives, 23, footnote 121 refers to Schechtman’s narrative view of the self.

³³ Marya Schechtman. *Staying Alive: Personal Identity, Practical Concerns, and the Unity of a Life*. (New York: Oxford University Press, 2014), 100.

circumstances.³⁴ Dworkin says that “death is... a peculiarly significant event in the narrative of our lives... with everything about it intensified, under a special spotlight.”³⁵ Given the significance of death, people usually want to die in a way that reinforces their critical interests since those are the interests that are most meaningful. In her discussion of Dworkin, Penney Lewis says that critical interests “survive the loss of capacity and that respect for these important interests requires the implementation of an advance directive that promotes them.”³⁶ Ultimately, critical interests represent the kind of life that a person wants to lead and the kind of person that they want to be based on their deepest values and beliefs. According to Dworkin, critical interests are more significant than experiential interests since they are deeply entwined with one’s identity. Moreover, they are the interests that are communicated in advance directives.

Given that critical interests are often incorporated in advance directives, Dworkin believes that advance directives should be respected even if the person to whom they apply expresses a conflicting desire when they are incapable. For instance, if we take the example of the Jehovah’s Witness who creates an advance directive that says that they do not want to receive a blood transfusion, then Dworkin would say that this instruction should be followed even if they express a conflicting desire to live at a time of incapacity. In his discussion of advance research directives and the principle of precedent autonomy, Tom Buller says that “respect[ing] the wishes of the now incompetent patient is to override a *legitimate* exercise of the individual’s autonomy”³⁷ suggesting that legitimate autonomous choices are reflected in advance directives.

³⁴ Rebecca Dresser, “Dworkin on Dementia: Elegant Theory, Questionable Policy,” *The Hastings Center Report* 25, no. 6 (Nov-Dec 1995): 33.

³⁵ Dworkin, *Life’s Dominion*, 209.

³⁶ Penney Lewis, “Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?” *European Journal of Health Law* 13 (2006): 221.

³⁷ Tom Buller, “Advance consent, critical interests and dementia research,” 702 (italics added by me).

Dworkin supports this message since, according to his view, individuals who are unable to make autonomous decisions can and should be treated as if they are capable by respecting their advance directive.³⁸

While not every person will necessarily consider sexual interests to be critical to their identity, some people may strongly identify with some sexual practices and values. A good example of the way that sexual decisions may be critical to one's identity is that of lesbian separatism.³⁹ Lesbian separatism is "the radical view that the best answer to patriarchy is to live as a lesbian and to focus one's efforts on lesbian communities."⁴⁰ Someone who identifies as a lesbian separatist embraces the sexual preferences of lesbianism specifically because of their critical values and interests when it comes to patriarchy. Another example might be a person who grew up in a devout Christian household and embraces the idea that monogamous relationships ought to be maintained throughout the course of one's life, even if one is unhappy, forgets the relationship due to dementia, etc. While it may not necessarily be the case that everyone will have sexual preferences that they classify as critical interests, these two examples show how critical interests can be relevant when it comes to sexual acts.

Similar to advance medical directives, *advance sexual directives* can be used to ensure that people have their autonomous sexual decisions outlined and respected when it comes to their critical sexual interests. Advance sexual directives would allow individuals to document their autonomous sexual preferences just in case they become incapable of consenting due to a dementia diagnosis.

³⁸ Ronald Dworkin, *Life's Dominion*, 225.

³⁹ It is not necessarily the case that a person's sexuality will always contribute to their identity in a meaningful sense. Thanks to Katy Fulfer for bringing this question to my attention. While I am still inclined to suggest that a person's sexual decisions will often contribute to their identity, there may be cases where a person's sexual choices are not reflective of any critical interests.

⁴⁰ Dea, *Beyond the Binary*, 59.

If we apply Dworkin's view of advance directives to the sexual domain, then advance sexual directives would need to be followed as a matter of respecting a person's critical interests. For instance, suppose we take the example of a Christian who has a critical interest in maintaining a monogamous sexual relationship. If this person outlined her preference in an advance sexual directive, and if she became unable to consent to sex in typical ways because of a dementia diagnosis, then looking to her advance sexual directive may allow her prior autonomous choice to be honoured; her advance sexual directive would count as a type of consent based on the principle of precedent autonomy. Dworkin's view would probably say that there are ethical reasons to honour the sexual practices that are outlined in an advance sexual directive even if a person is sexually passive/silent in the moment; the justification would be the significance of precedent autonomy in relation to critical interests.

There is some ambiguity about how Dworkin's view would respond to a person who explicitly dissents to a sexual act that was agreed upon in their advance sexual directive. His view seems to suggest that it may be ethically defensible for a person's dissent to be ignored since an advance directive is supposed to represent legitimate autonomous decisions. If advance sexual directives outweigh a person's present preferences, however, then this may pose a problem when it comes to balancing a principle of autonomy/precedent autonomy with that of non-maleficence. Engaging in sexual acts with someone who does not consent would result in sexual assault, and the associated harms of an assault may not outweigh the benefits that may come from respecting prior autonomous preferences.

3- *In Opposition to Advance Directives*

Rebecca Dresser's discussion on personal identity and advance directives directly opposes Dworkin's view, illustrating some general problems that ought to be considered for a framework of advance sexual consent. Dresser suggests that advance directives do not need to be followed because people change in significant ways; the person who created the directive when they were capable is not the same person as when they become incapable. Based on her conception of personhood, Dresser suggests that experiential interests ought to be the primary concern for people with dementia rather than the critical interests that are outlined in advance directives; the person with dementia is different than their non-dementia self.

Dresser's perspective on personhood and personal identity is influenced by, though not the same as, Derek Parfit's personal identity theory. According to Dresser's interpretation of Parfit's view, one's identity varies over time "depending on the strength of connectedness and continuity between an individual's psychological features, such as memories, intentions, beliefs, and desires."⁴¹ The way to determine whether one's connectedness and continuity have changed significantly is by considering whether one's current beliefs, desires, values, etc. are discontinuous from former beliefs, desires, values, etc. If an individual's connectedness and continuity have changed to a significant extent, then they are no longer the same self; the parts of one's life that are no longer psychologically connected to one's central identity can be referred to as "other selves".⁴² Parfit's theory responds to a primary question about personal identity, namely, the reidentification question. The reidentification question considers how a single entity persists through change by trying to supply criteria to explain why a person that exists at T2 is

⁴¹ Rebecca Dresser, "Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law," *Arizona Law Review* 28 (1986): 380.

⁴² Rebecca Dresser, "Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law," 380.

the same person that existed at T1.⁴³ This question does not solely focus on whether a person is the same at T1 and T2 but rather what it is that makes an individual the same person at two different time slices; what are the relations amongst each of the segments of a person's life that allow a single entity to persist through change?⁴⁴ Parfit responds to this question by saying that psychological continuity is what makes a person the same person at two different time slices. If there are discontinuities in a person's psychological continuity then their identity has changed.

According to Dresser, it seems that a person with dementia may sometimes be a different person than their pre-dementia self. A person *without* dementia at T1 who holds certain beliefs, and the seemingly same person *with* dementia at T2 who holds contrasting beliefs would be seen as two different selves. This has some important implications for whether the principle of precedent autonomy works to preserve a person's autonomy and whether advance directives ought to be followed.

Advance directives assume that a competent person's interests and conception of the good will remain the same when they become incompetent, which is a problematic assumption from Dresser's perspective. As Dresser says, if one's mental or physical health changes because of a dementia diagnosis or otherwise, then one's corresponding "beliefs, values, and goals, and hence... interests may change as well."⁴⁵ The idea that a person's interests will likely change when their health changes (and, consequently, that an advance directive may not accurately reflect what a person wants at the time that the directive becomes relevant) is reinforced in Daniel Gilbert's discussion of happiness and future decision-making. In *Stumbling on Happiness*, Gilbert says that people are typically bad at making decisions about what will make

⁴³ Schechtman, *The Constitution of Selves*, 7.

⁴⁴ Schechtman, *The Constitution of Selves*, 8.

⁴⁵ Dresser, "Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law," 381.

them happy at future points in time; most individuals have a challenging time “imagining a tomorrow that is terribly different from today”⁴⁶ and so we “project our present selves into the future.”⁴⁷ If Gilbert is right — if we are almost entirely ignorant about our future circumstances and about what our future selves will want — then this poses a problem for the precedent autonomy view and advance directives; no one will be able to develop advance directives that accurately reflect their future selves.

Dresser says that when one’s interests change because of a dementia diagnosis, then one’s previously expressed interests and values are irrelevant because the person is no longer the same self. If one’s prior interests and values are irrelevant then the concept of precedent autonomy is also unimportant; the principle is only pertinent insofar as the same person exists over a sustained period of time. If a person with dementia is no longer the same as their non-dementia self then there is no need to try to respect their previously expressed autonomous decisions.⁴⁸ In fact, respecting these decisions may be seen as ethically illicit from the perspective of autonomy since they no longer represent the right person. According to Dresser, advance directives “originate in insufficient or mistaken information”⁴⁹ since they do not reflect a person’s present interests or desires. Consequently, she says that advance directives do not need to be followed even if a person is unable to make autonomous decisions. Dresser’s argument that a person’s prior preferences and values about their future may be mistaken is especially plausible (and concerning) in the context of disability and dementia, given the stigma that exists about both of these populations. Rather than prioritizing critical interests and

⁴⁶ Daniel Gilbert, *Stumbling on Happiness* (New York: Alfred A. Knopf, 2006), 114.

⁴⁷ Gilbert, *Stumbling on Happiness*, 114.

⁴⁸ Dresser, “Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law,” 381.

⁴⁹ Dresser, “Dworkin on Dementia: Elegant Theory, Questionable Policy,” 35.

precedent autonomy, Dresser's view suggests that experiential interests ought to be prioritized. This means that a person with dementia should be permitted to engage in activities that contribute to happy experiences.

Dresser's criticism of advance directives is relevant to considering advance sexual directives as well. If a person with dementia is different than their pre-dementia self, then any sexual decisions that are expressed in advance sexual directives may be moot. Advance sexual consent would be futile in these cases since the person with dementia would not have any prior autonomous decisions *as a person with dementia*. In this kind of case, it may be ethically illicit for them to only be allowed to engage in the kind of sex that was consented to in an advance directive from the perspective of precedent autonomy (which is what Dworkin's view suggests). According to Dresser, a person's directive is "the illegitimate imposition of one person's autonomous choice on another person"⁵⁰, which is obviously a problem if we want people to be able to autonomously consent to sex for themselves.

Dresser's critique of advance directives and her perspective of people with dementia has some similarities to what Laurie Ann Paul refers to as a "transformational experience".⁵¹ Paul describes transformational experiences in the following way:

The idea is that, when you find yourself facing a decision involving a new experience that is unlike any other experience you've had before, you can find yourself in a special sort of epistemic situation. In this sort of situation, you know very little about your possible future... [a]nd so, if you want to make the decision by thinking about what your lived

⁵⁰ Lewis, "Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?," 221.

⁵¹ Kyle Boerstler, "The challenge of transformative experiences for advance directives: predicting a future with Alzheimer's disease," *Palgrave Communications* 34, (2017): doi:10.1057/palcomms.2017.34.

experience would be like if you decided to undergo the experience, you have a problem.⁵²

Paul gives various examples of transformational experiences. From my perspective, one of the most interesting examples that she considers is that of becoming a vampire. In this example, Paul presents an individual who has to choose whether or not to become a vampire.⁵³ The person's friends have all become vampires and they all speak positively about the experience, but the problem is that it is impossible for this person to make an informed decision about becoming a vampire without actually becoming one. Becoming a vampire will change their life; it will change them in a significant way that is impossible to understand through testimony alone. Paul notes that prior to having a transformative experience a person is in "a special kind of epistemic poverty, keyed to her inability to grasp crucial information about the nature of her future experiences"⁵⁴; this seems to, at least in part, support Dresser's claim that it may be futile to create advance directives since it is impossible to accurately know one's what one's preferences will be at a time of incapacity.

According to Paul, there are two kinds of transformative experiences that exist. The first is epistemically transformative experiences. Epistemically transformative experiences give people new information upon having the experience(s). So, when a person has a new experience that could not have been learned without having the experience, then they have an epistemic transformation. An epistemic transformation is when a person's "knowledge of what something is like, and thus her subjective point of view, changes."⁵⁵ The second type of transformative

⁵² L.A. Paul, *Transformative Experience* (New York: Oxford University Press, 2014), 2.

⁵³ Paul, *Transformative Experience*, 2.

⁵⁴ Paul, *Transformative Experience*, 10.

⁵⁵ Paul, *Transformative Experience*, 11.

experience is a personally transformative experience. Personally transformative experiences change “how you experience being who you are.”⁵⁶ It is possible to have one of these transformative experiences without the other. An example of an epistemically transformative experience might be trying a new type of fruit.⁵⁷ Trying a new fruit would be epistemically transformative, but unlikely personally transformative. Conversely, certain experiences might be personally transformative in that a person’s self might change as a result of some event, even though the event might be epistemically familiar. For instance, a person might go to their workplace one day and receive an e-mail that contains content which is personally transformative. Their workplace and the practice of checking e-mails are not epistemically unfamiliar, but the person experienced a personally transformative experience because of the content included in this particular e-mail.

Paul’s examples of transformative experiences consider situations in which a person can choose to pursue or not to pursue a particular act— this is different than a dementia diagnosis since people cannot (and do not) choose to have dementia. An important similarity, however, is that in Paul’s examples it is epistemically impossible to make an informed choice about pursuing certain things after a transformational experience, which is similar to the way that it is epistemically impossible to create an informed advance directive prior to a dementia diagnosis. Although Paul does not consider dementia as one of her examples, a dementia diagnosis seems to involve transformational experiences.⁵⁸ Dementia is epistemically transformative because it is impossible to know what it like to have dementia without actually having it. Also, it is

⁵⁶ Paul, *Transformative Experience*, 17.

⁵⁷ Paul, *Transformative Experience*, 15.

⁵⁸ Boerstler, “The challenge of transformative experiences for advance directives: predicting a future with Alzheimer’s disease”.

impossible to make future decisions about dementia based on other people's testimonies given the range of experiences (both positive and negative) that are communicated by and about people with dementia. Furthermore, dementia can be personally transformative since individuals' personalities, and perhaps identities, change (just like anyone else). Again, it is important to highlight that Paul's examples focus on cases where a person can decide to pursue a particular act, which is importantly different from dementia since a person does not decide to have this illness. The reason that Paul's examples may be helpful when it comes to considering advance sexual directives (and advance directives in general) is because a person's inability to know what a life with dementia would be like poses a challenge when it comes to developing advance directives. In fact, Paul's examples may be pertinent to anyone who experiences a change in their values, cares, concerns, pleasures, needs, etc. irrespective of dementia.

According to Paul, having transformative experiences that are epistemically and personally transformative are salient from a decision-making standpoint. The primary concern about transformative experiences and decision-making is that it is impossible "to meet an acceptable rational, normative standard when making certain epistemically and personally transformative decisions from the subjective point of view."⁵⁹ In order to make decisions about transformative experiences, our standard decision-making methods may have to change; this may be relevant to deciding if a person should develop an advance directive. This is part of the reason that Dresser opposes Dworkin's arguments about advance directives, specifically since it is impossible for people to make decisions for a future point in time to which they do not have access. Dresser's opposing arguments about advance directives can be applied to advance sexual

⁵⁹ Paul, *Transformative Experience*, 20.

directives in the same way. A person's sexual values may change upon being diagnosed with dementia and there is no way to determine whether and/or what these values may be in advance.

4- Applications of Advance Sexual Directives

Advance sexual directives would enable people to express their sexual preferences and consent just in case they become incapable of consenting at a future point in time because of a dementia diagnosis. One of the primary concerns about advance directives in general is whether they are and/or ought to be permanently binding if a person communicates conflicting preferences at a time of incapacity. So, how might we respond to this discrepancy when it comes to sexual decisions? One way might be to turn to the medical domain and consider how advance medical directives are implemented in practice when it comes to challenging cases. The challenging cases that I am thinking about are when a person with dementia seems to have a genuine interest in pursuing something other than what is communicated in their directive. Examining how these kinds of cases are managed in the medical domain may help to respond to the question of whether and/or how much advance sexual directives ought to be considered.

In cases of advance medical directives, there may be times when someone's current medical preferences conflict with the content of their advance directive, which is Dresser's primary concern. Moreover, in cases involving people with dementia, it is often impossible to know whether their underlying preferences, or second-order desires, have changed, causing their current preferences to diverge from prior preferences. The only evidence that we typically have for a person's changing preferences is based on whatever is being communicated or expressed, which may only reflect their first-order desires.

In his discussion of free will and personhood, Harry Frankfurt discusses first-order and second-order desires. First-order desires are those that influence a person to act in a certain way—these actions are guided by a person’s first-order *volition* or *will*.⁶⁰ For instance, one’s desire to yell at an intoxicated person who is disturbing one’s sleep would be a first-order desire.⁶¹ Second-order desires are the desires that one has about one’s first order desires. So, one’s desire to *not* act on one’s desire to yell at the intoxicated individual would be a second-order desire. Second-order desires are sometimes considered to be intrinsic (e.g. the desire to not yell is desirable *for its own sake*) and sometimes considered to be instrumental (e.g. one’s second order desire to not yell at the person is because of the instrumental desire to not have rocks thrown at one’s window after yelling).⁶² Either way, the point to highlight is that a person with dementia may express a first-order desire about a particular medical preference without giving any rationale for their expressed preference—their underlying (second-order) preference or desire will often remain unknown because their dementia symptoms may inhibit them from being able to communicate it. For instance, suppose a person creates an advance directive that says that they want to remain on life-sustaining treatment to increase the number of years that they live (perhaps this directive is motivated by the fact that they want to live to see their grandchildren). Then, after being diagnosed with dementia and losing their capacity to consent to most treatments, suppose they are required to remain on dialysis to sustain their life. According to their advance directive, receiving and remaining on dialysis would be in keeping with their prior autonomous choice. Suppose, however, that after undergoing a few dialysis treatments the

⁶⁰ Harry G. Frankfurt, “Freedom of the Will and the Concept of a Person,” *The Journal of Philosophy* 68, no. 1 (1971): 5–20. Dennis Loughrey, “Second-order Desire Accounts of Autonomy,” *International Journal of Philosophical Studies* 6, no. 2 (1998): 212.

⁶¹ Tim Schroeder, “Desire,” *The Stanford Encyclopedia of Philosophy* (Summer 2017 Edition), ed. Edward N. Zalta, <https://plato.stanford.edu/archives/sum2017/entries/desire/>.

⁶² Schroeder, “Desire.”

person yells “No!” and becomes panicked every time they are brought to the dialysis unit; their reason for saying “no” and altering their preference remains unclear (whether or not they still want to live is unknown). Another example might be a Jehovah’s Witness who has an advance directive that says that they do not want to receive blood products even if blood products are required for them to live. Then, suppose that they subsequently express a desire to live when they have dementia and are *incapable* of making an autonomous choice, and respecting their desire to live would require the receipt of blood products. In both cases, the person’s motivation for their new preference is often unknown.

In the above types of scenarios, family members and clinicians will often try to have a discussion with the person with dementia (if possible) to try to understand the rationale for their changed preference(s). Furthermore, they may take the person’s expressed preferences into account even if their reasoning is irrational or unknown. The reason that incapable preferences are sometimes taken into account is twofold. First, it is important that the principle of respect for persons is followed, which is pertinent irrespective of whether a person can make their own autonomous decisions. Second, and perhaps most importantly, it is sometimes the case that a person’s present preferences may result in a greater benefit and/or less harm, whereas following an advance directive may be seen as more harmful. The justification for overriding an advance directive in certain circumstances (and following a person’s non-autonomous preference) is typically because the principle of autonomy/precedent autonomy often has to be balanced with other bioethical principles. The principle of non-maleficence (prevention from harm) is one of the primary principles often discussed in bioethics, and there might be times when this principle needs to be prioritized in comparison to the principle of autonomy/precedent autonomy because of the amount of harm that a particular autonomous/prior autonomous act may cause. If forcing

someone to receive or to not receive treatment can be seen as maleficent, then it is sometimes thought that prioritizing a principle of non-maleficence can be justified as more important than autonomy/precedent autonomy.

If we apply this process to advance sexual directives, then it seems that a person's prior consent could be withdrawn upon their expressing dissent and/or their prior refusal to consent could be potentially overridden by a new expressed preference. This is the same way that current sexual consent frameworks operate where present consent/refusal to consent is weighed more heavily than prior decisions. If a person's advance directive says that they only consent to have sex with their spouse and the person refuses to consent at the time of a sexual act, then engaging in sex (in accordance with their advance directive) would be ruled out. Unwanted sexual interactions can cause harm even if a person is not able to fully comprehend their dissent—this was illustrated in the case of *R. v. J.A.* So, if a person with dementia expresses a disinterest in sex even if they consented in their advance sexual directive then that dissent ought to be explored. Similarly, suppose a person expresses a desire to have sex in a way that conflicts with their advance directive. In this case, the person's current interests ought to be considered, and, if we follow the same process as advance medical directives, then other individuals would need to determine if their former autonomous preferences should be overridden.

While turning to the medical arena may be helpful for managing advance sexual directives in certain circumstances, there are some important differences between the sexual and medical domains. One difference is that in cases of medical decisions, an advance directive *would* be followed if one is passive (specifically if a substitute decision maker consents on a person's behalf); this may be a potential problem when we consider passivity in relation to sexual cases. According to current standards of sexual consent, silence and passivity do not equal

consent, and people can be charged with assault if their partner does not explicitly consent to participate (e.g. if they are passive); this is especially pertinent for people who are socialized to be passive. Since many people with dementia are passive and since this passivity might be exacerbated for people who come from certain oppressive backgrounds, it seems that passivity in the sexual domain would need to be treated differently than how it is managed in the medical domain. It would be challenging to determine whether a person with dementia who is passive *actually* wants to engage in a sexual act in accordance with an advance sexual directive, or whether they are passive because of fearfulness or because of how they were socialized to behave. For instance, if we take the previously mentioned example of a deferential person who typically consents to have sex when their partner initiates it, and if this person is diagnosed with dementia and remains passive, then this may pose some challenges: Do they or don't they want to participate? Could it be harmful if their prior preferences are respected in this kind of case? Should we assume that they want to be deferential? There is some reason to be cautious about proceeding to have sex with a passive participant with dementia even if they consented in advance of their incapacity; this is because of the intrusiveness of sex and the distinct types of harms that could result from pursuing unwanted sexual acts.

5- A Response to Dworkin and Dresser

In this section, I will consider Alexander Boni-Saenz's approach to advance sexual consent and people with dementia. Boni-Saenz recognizes that there is a disagreement between Dworkin's and Dresser's views of advance directives that would plausibly apply to the sexual domain. In response, Boni-Saenz proposes a novel theory of advance sexual consent as a

possible way to bridge this gap. His approach allows people to prospectively consent to sex while at the same time protecting people with dementia from experiencing undue sexual harm.

Boni-Saenz's model of advance sexual consent bridges Dworkin's and Dresser's views. His proposal is called a "consensus of consents."⁶³ A consensus of consents is when a self at T2 agrees to a decision that was consented to at T1. It is when "[t]he Time 1 self will provide prospectus consent to sex, while the Time 2 self will token contemporaneous consent. Boni-Saenz says that "when this occurs, there is a *consensus of consents*, and theorists from both sides of the philosophical divide would likely agree that sexual advance directives then serve important purposes."⁶⁴ While Dresser may disagree with the likelihood of a consensus of consents occurring, she may agree with the outcome since it would be taking the person with dementia's current interests into account. So, suppose someone creates an advance sexual directive that outlines their decision to have sex with their long-time partner even if they are unable to consent in accordance with conventional norms. In this case, the consensus of consents suggests that it would be ethically licit for this person with dementia to have sex with their partner from the perspective of autonomy if they express a willingness to participate at the relevant time; the person must show that they are in consensus with their former consent.

The consensus of consents recognizes prior autonomous decisions as important, thereby respecting Dworkin's primary concern about precedent autonomy and critical interests. At the same time, however, this model recognizes that a person's interests and decisions may change upon being diagnosed with dementia, thereby responding to Dresser's main concern. According to this model, if one is *not* in agreement/consensus with one's prior autonomous decision(s) then a consensus of consents has not been obtained and it would be ethically illicit to proceed with the

⁶³ Boni-Saenz, "Sexual Advance Directives," 26.

⁶⁴ Boni-Saenz, "Sexual Advance Directives," 26

prior choice from the perspective of autonomy. The former decision and the later expressed preference must coincide.

Boni-Saenz rejects passivity as a meaningful contributor to gauging ethically licit sexual consent. He says that in order to ensure that people with dementia want to participate in sex in accordance with their advance directive, there must be an affirmative verbal or nonverbal consent, such as a verbal “yes” or an explicit willingness to participate (e.g. sexual initiation).⁶⁵ As described in Chapter Three, Boni-Saenz introduces a case that shows how different communication styles are important to consider. Specifically, Boni-Saenz describes how Henry Rayhons’s wife with dementia would (according to Henry) initiate sex by asking, “Shall we play a little bit?”⁶⁶ which “points to the importance of involving people in the sexual decision-making process who know the person well.”⁶⁷

Boni-Saenz’s example makes a case for hybrid advance sexual directives; this is ultimately the framework that I argue would work best when it comes to considering advance sexual consent for people who cannot explicitly express affirmative agreement.⁶⁸ Hybrid advance directives are those in which a person’s sexual preferences would be outlined in an advance directive *and* a substitute decision maker would assist with any questions of interpretation, specifically if a person cannot explicitly communicate “yes” to sex. Although Boni-Saenz’s approach helps to address some of Dworkin’s and Dresser’s concerns, it requires affirmative consent from the person with dementia, and this may be impossible for some individuals with

⁶⁵ Boni-Saenz, “Sexual Advance Directives,” 39.

⁶⁶ Boni-Saenz, “Sexual Advance Directives,” 39.

⁶⁷ Boni-Saenz, “Sexual Advance Directives,” 39; Boni-Saenz suggests that a network of people who know the person with dementia well ought to be involved in interpreting advance sexual directives and consent.

⁶⁸ Boni-Saenz, “Sexual Advance Directives,” 12.

dementia. Hybrid advance sexual directives expand on Boni-Saenz's approach by allowing substitute decision makers to determine if a person desires to engage in sex in accordance with their directive *if they are unable to explicitly communicate their willingness to participate*.

6- Considering the "Consensus of Consents" and Advance Sexual Directives

A framework of advance sexual consent tries to balance a person with dementia's right to sexual expression with the importance of protecting them from harm. There are some possible limitations that need to be considered, however, when it comes to this managing this balance.

One potential limitation is that advance sexual consent may be most helpful for people who are interested in traditional forms of sex, thereby excluding people who are interested in non-traditional sexual activities. By "traditional forms of sex" I am referring to what Shrage and Stewart define as "vanilla" or "non-kinky" sex.⁶⁹ If the goal is to enable sexual expression *and to protect people from experiencing undue harm*, then it may be problematic if a person develops an advance sexual directive which states that they are interested in BDSM, for instance, given the increased potential for undue harm that may result when the person has dementia (even if they seem willing to participate). For example, if an individual (such as the person in the case of *R. v. J.A.*), typically consents to engage in asphyxiation, then this practice could, hypothetically, be consented to in an advance sexual directive and be seen as ethically licit at the time of the act if a person expresses a willingness to participate at T2. This practice of communicating one's desires in advance of a sexual activity aligns with how BDSM typically occurs, where people negotiate expectations, preferences, and limitations before the sexual act. This negotiation practice requires that a person can determine what they may want at a future point in time.

⁶⁹ Shrage and Stewart, *Philosophizing About Sex*, 13 and 262.

A concern about prospective consent to BDSM is that while these practices are meant to be sexually stimulating, people who practice BDSM (and who are capable of consenting to sex at the relevant time) have a “safe word” that can be used to communicate immediate dissent if they no longer want to participate. Upon communicating a “safe word”, the BDSM activity must stop. This is negotiated in advance of the sexual interaction. The main concern about people with dementia participating in BDSM practices (or other non-traditional sexual activities) is that they may be unable to remember and/or articulate any agreed upon “safe words” if they struggle with memory loss and/or language and communication challenges.

Given that dementia is a disease that differs for people based on their stage of diagnosis and corresponding experiences, someone who is in the early stages of dementia might be able to communicate a refusal of consent when it comes to non-traditional sexual practices through the use of “safe words”, but this is not guaranteed. Moreover, determining the stage at which one is no longer able to remember and communicate safe words would be challenging, if not impossible, to confirm. While someone might be able to communicate their preferences one day, there is no guarantee that this same person will be able to effectively communicate on the subsequent day. Also, people from certain oppressed and marginalized backgrounds might be less willing and/or less able to dissent to imposed or unwanted sexual activities if they were socialized to behave in certain ways. For instance, a woman with dementia might be less willing or able to express explicit dissent if she was socialized to be sexually passive. These kinds of considerations would need to be considered in cases of advance sexual directives for non-traditional preferences.

The above limitation might make it such that only certain sexual acts that are positively consented to (as opposed to passively received) in accordance with Boni-Saenz’s proposal and a

hybrid model would be permissible, or perhaps only some kinds of practices ought to be included in advance sexual directives in order to ensure that the principles of precedent autonomy and non-maleficence can both be respected. This possible resolution may be viewed as discriminatory and unfair, however, when it comes to recognizing and enabling a person's right to sexuality and autonomy. Rather than excluding certain practices from advance sexual directives entirely, perhaps additional safeguards could be put in place for people with dementia who want to engage in less traditional (and potentially riskier) forms of sex; a model that is similar to Pineau's communicative sexuality may help since a sexual partner would need to check in with the person with dementia throughout an interaction to make sure that they want to participate.

A second potential problem of advance sexual consent, and, specifically the consensus of consents, is the possibility of imposed values and preferences; this is always a concern when other people are involved in decision-making processes, which would be the case under a hybrid model.⁷⁰ In order to ensure that a person's affirmative consent is accurately interpreted by other individuals, it may be helpful to look at how the person used to express consent. Moreover, similar to Chapter Three's supported decision-making framework, loyal supporters who can interpret a person's consent to sex (or lack thereof) may need to be involved in a decision-making process. The concern about imposing values was also mentioned in Chapter Three, and there is no way to completely eliminate this possibility.

If we take a framework of advance sexual consent seriously then any kind of autonomous sexual preference should be able to be included in advance sexual directives. In order to mitigate the potential for undue harm, Boni-Saenz says that a person with dementia must affirmatively agree to participate. I suggest, however, that a hybrid model would allow others to interpret a

⁷⁰ Doll, *Sexuality and Long-Term Care*, 115.

person's willingness to participate even if they cannot explicitly affirmatively consent or express a volition to participate.⁷¹ There are still some potential challenges to consider since certain sexual preferences may put people at a greater risk of harm. Also, the possibility of imposing one's values onto a person with dementia may increase on a hybrid model.

7- Conclusions

This chapter considered a way for people with dementia to participate in a form of autonomous sexual decision-making by introducing a framework of advance sexual consent. The purpose of advance sexual consent is to allow people to develop advance directives that outline their sexual preferences. This would, theoretically, allow people with dementia to engage in ethically licit sexual practices (from the perspective of autonomy) if they are unable to communicate their autonomous consent in typical ways because of their dementia diagnosis.

One reason that advance sexual directives ought to be considered is because advance directive practices exist in other contexts, and they are justified by the principle of (precedent) autonomy. In both the medical and financial domains, people can document their autonomous decisions and consent/refuse to consent to certain acts just in case they become incapable of making their own decisions at a future point in time. Then, if they become incapable, the principle of precedent autonomy suggests that their prior autonomous decisions ought to be respected. Insofar as sexual interests can be critically important to a person's health, well-being, and identity, then it seems that there is no good reason to necessarily exclude the sexual domain.

Advance medical directives have been contested in the philosophical literature, and these contestations are relevant to considering the ethics of advance sexual directives. Advocates of

⁷¹ It is possible that Boni-Saenz may agree with this idea (irrespective of whether a person has a proxy directive designating a decision-making agent) since he recognizes an inability to express affirmative agreement as a potential limitation (Boni-Saenz, "Sexual Advance Directives," 39).

advance directives, such as Dworkin, suggest that advance directives provide a way to respect the principle of precedent autonomy. Dworkin says that advance directives ought to be respected even if a person expresses conflicting preferences in a future non-autonomous state.

Contrastingly, however, some theorists question the relevance of advance directives because of the idea that people with dementia sometimes change in ways that conflict with their former, non-dementia selves. Rebecca Dresser is the main theorist who argues against Dworkin's view. Both perspectives are important to considering the ethical implications of advance sexual directives.

Given that Dworkin's and Dresser's views are polarized and there is no clear way to respond, I initially looked to the medical domain to see how advance directives are managed. The medical domain provides some guidance in terms of how advance decisions can be considered, however, the sexual domain is importantly distinct. In order to respond to some of the complexities of sexual acts, I introduced Boni-Saenz's "consensus of consents" framework. Boni-Saenz's view responds to Dworkin's and Dresser's disagreement by recognizing the importance of precedent autonomy and considering the possibility of changing preferences—he says that a person's prior autonomous sexual decision(s) ought to be respected if they affirmatively agree at the present time. I proposed to expand Boni-Saenz's view through a hybrid framework so that all people with dementia can have their advance sexual directives and current decisions considered even if they cannot explicitly and affirmatively consent to engage in sex; a hybrid framework would allow substitute decision-makers to consider a person's prior expressed preferences in relation to their present desires so that all people have the opportunity to achieve a consensus. This view is a step forward in terms of enabling autonomy through advance sexual directives while at the same time protecting people from undue harm. A hybrid model of advance

sexual consent may encounter certain problems, however, when it comes to non-traditional sexual preferences where the likelihood for experiencing harm is high. The possibility of other individuals imposing their values onto a person with dementia is also a problem that needs to be considered.

Chapter 5

A Framework of Prioritizing Well-Being

The previous two chapters introduced frameworks of sexual consent for people with dementia by considering different conceptions of autonomy. This was based on the idea that the principle of autonomy is ethically significant when it comes to considering sexual acts, and so a person's autonomy would need to be taken into account when approaching cases of sex and dementia. This chapter moves away from autonomy and considers a new way to approach the topic. The focus of this chapter is to introduce what I am referring to as "a framework of prioritizing well-being" by considering desire, pleasure, and happiness as relevant factors.

A framework of prioritizing well-being responds to the question "*if well-being is important for persons with dementia then how do we enable it?*" by suggesting that sexual acts that satisfy desires, lead to pleasure, and/or create happiness may help. I suggest that there is a *prima facie* reason to believe that having a person's desires satisfied, experiencing pleasure, and being happy are all good things that can contribute to a person's well-being, and it is possible to satisfy these elements independently of one another when it comes to the sexual domain. In their discussion of well-being, economists David G. Blanchflower and Andrew J. Oswald say that it is possible to distinguish between two types of well-being; well-being can be associated with one's life as a whole and it can be associated with a single area of life. The terms "context-free" and "context-specific" are used to reflect these two types of well-being.¹ This chapter focuses on prioritizing well-being in a "context-specific" sense, namely, in a context that focuses on sexual acts.

¹ David G. Blanchflower and Andrew J. Oswald, "Money, sex and happiness: an empirical study," *The Scandinavian Journal of Economics* 106, no. 3 (2004): 395.

I describe my motivation for considering this framework in the next section. I then explain why we ought to care about well-being when it comes to people with dementia, and why elements of desire, pleasure, and happiness are relevant. Subsequently, I explain how this framework would work by considering each of the three elements. I suggest that a practice of assent is especially helpful when it comes to determining whether a person has sexual desires and is experiencing sexual pleasure. Assent is often used in the medical domain so that people who are not capable of consenting to treatment or other medical decisions can still contribute to the decision-making process by affirmatively agreeing to participate. After introducing how a framework of well-being would work, I describe a practical example where it seems that cases of sex and dementia are approached in a way that supports this framework.

It is important to note that this framework does *not* consider desire, pleasure, happiness, and, ultimately, well-being, to be types of sexual consent. Rather, this framework focuses on enabling and prioritizing well-being above other factors that are typically seen as important (e.g. autonomy and consent). The motivation for this framework (and every other framework in this dissertation) is to respond to the specific needs and characteristics of persons with dementia. I argue that one way to respond to the needs of this population is to prioritize their quality of life and well-being, which can be done by satisfying desires, experiencing pleasure and/or gaining happiness.

1- A Motivation to Consider Well-Being

My motivation for introducing and considering a framework of well-being was prompted by two cases. The first case occurred in the United States. I sketched this case in Chapter Two and so I will only briefly describe some of the main points as they relate to this chapter. The

second case was described recently in Canada and it reflects upon similar themes as the case from the United States.

As described in Chapter Two, the story of former Supreme Court Justice Sandra Day O'Connor made headlines in 2008. Justice O'Connor's husband (John O'Connor) was diagnosed with dementia at the age of seventy-seven. After moving into a centre for Alzheimer's, John fell in love with another resident who was identified as Kay.² Prior to his admission into the centre, John was unable to recognize his family (including Justice O'Connor) and he was severely depressed. His depression subsided after commencing a relationship with Kay. Justice O'Connor was required to inform the centre about how to proceed upon being informed of her husband's new relationship; she had to give (or decline to give) permission. In the end, Justice O'Connor permitted John to pursue his new relationship. Prioritizing John's well-being was at least part of the reason that Justice O'Connor approved of her husband's new relationship.

According to the manager of John O'Connor's nursing home, this scenario is not an isolated case; people with dementia sometimes want to pursue new intimate relationships upon being housed at the centre for Alzheimer's. In fact, a similar case to John's recently made headlines on the Canadian Broadcasting Corporation. In a 2017 segment on *Out in the Open*, Bob Best and his daughter Cassandra Trach were interviewed about Bob's wife/Cassandra's mother, Karen Best. Karen was fifty-nine years old at the time of her family's interview and she was living in a nursing home with diagnoses of frontal lobe dementia and early onset Alzheimer's. The reason for the interview was to talk about sexual consent and dementia. In the interview, Bob Best said that one day "he received a call from Karen's [nursing] home notifying him that they found her in bed with another man — who also has dementia — with no pants

² Sherwell, "Judge lost husband to Alzheimer's - and love."

on.”³ Bob Best said that “[i]t was one of these things that the home felt that every time they caught or saw or found my wife in a 'compromising' position, they would have to call myself or my daughter. And, it got to be a fair number of times. I remember one weekend there were four phone calls.”⁴ So, similar to the case of John O’Connor, Karen’s family was required to discuss their wife’s/mother’s new intimate relationships, and similarly to Justice O’Connor, Bob and Cassandra chose to support Karen’s intimate activities insofar as they contributed to her happiness. In his interview, Bob Best posed the following questions: “the bottom line is, is she happy? Is she having a meaningful life right now? Because [i]f we took this [intimate relationship] away from her, what would she have?”⁵ This sentiment depicts the possibility that a person with dementia’s happiness and well-being may be salient when it comes to considering sexual acts.⁶

The manager of John O’Connor’s nursing home said that family members approach these cases in different ways. Some family members are distressed when they learn about their loved one engaging in a new intimate relationship. However, “[there are also people on] the other end, the opposite spectrum, that it's OK that they have somebody to make [the person with dementia]

³ Bob Best and Cassandra Trach, “What does consent look like when you have dementia?” interview by *Out in the Open*, Canadian Broadcasting Corporation, May 21, 2017, <http://www.cbc.ca/radio/outintheopen/sexual-consent-1.4123222/what-does-consent-look-like-when-you-have-dementia-1.4123272>.

⁴ Best and Trach, “What does consent look like when you have dementia?”

⁵ Best and Trach, “What does consent look like when you have dementia?”

⁶ John Portmann, *The Ethics of Sex and Alzheimer’s* (New York: Taylor and Francis, 2014), xv; Based on the available descriptions of John O’Connor’s and Karen Best’s cases, it is not completely clear whether they engaged in sexual relationships and/or what kinds of sexual acts they may have been involved in. The news articles regarding John were relatively unspecific, though Professor John Portmann describes the case as involving “sexual activity” and he says that Justice O’Connor’s decision was an act of “sexual generosity” (138 and 143). In the second case, Bob Best stated that his wife was never “caught in the moment” so the details of her intimate relationships were unknown (Best and Trach, “What does consent look like when you have dementia?”). However, since the topic of the news program was sex and dementia, we can probably assume that his wife was engaging in some form of sexual act.

happy”⁷, such as Justice O’Connor and Karen Best’s family. Although sex is often a taboo topic and not everyone will approach sex and dementia in the same way, these cases show that people with dementia may desire to engage in sexual acts and satisfying these desires can contribute to their well-being.⁸ Furthermore, a person’s well-being and quality of life are sometimes prioritized above other ethical values (e.g. autonomy) for people with dementia.

In addition to the cases of John O’Connor and Karen Best, some of the other cases from Chapter Two also mentioned aspects of well-being as potentially relevant to the ethics of sex and dementia. In the first case of Peter Adcock, the staff at the care home noticed that both Peter and the resident appeared to be enjoying themselves when they were engaging in sexual acts.⁹ In the second case of Henry Rayhons, the staff at his wife’s care home said that she was always happy to see her husband and she initiated sexual acts, demonstrating desire.¹⁰ In the third case of the Windmill Manor nursing home, the woman was apparently much happier when she was with her sexual partner; physically forcing her and her partner to separate caused distress. If a person’s sexual desire, pleasure, and happiness are relevant to considerations of well-being and quality of life, then this may serve as a reason to promote this framework.

2- The Significance of Well-Being

There are a few reasons that satisfying desires, experiencing pleasure, and being happy are important to consider for people with dementia, the primary one being that each of these

⁷ Sherwell, “Judge lost husband to Alzheimer’s - and love.”

⁸ For instance, John O’Connor apparently courted his new lover on the Alzheimer’s ward, desiring to engage in some type of loving relationship.

⁹ Belluck, “Sex, Dementia and a Husband on Trial at Age 78.”

¹⁰ Belluck, “Sex, Dementia and a Husband on Trial at Age 78.”

elements can contribute to a person's well-being. I am using the term "desire" to define a state in which a person has a disposition to act.¹¹ Some theories suggest that desire that involves having a disposition to act to achieve some particular end (e.g. pleasure, goodness, etc.), but I am using a more open-ended definition. The desires that I am concerned with in this chapter are first-order desires, which we discussed in Chapter Four. The term "pleasure" refers to a satisfying experience; it is defined as "the affective positivity of all joy, gladness, liking, and enjoyment – all our feeling good or happy."¹² Finally, I am using the term "happy" to describe a mental state that often includes "life satisfaction, pleasure, or a positive emotional condition."¹³ A person's desire, pleasure, and happiness are determined by the person experiencing a particular sexual act and I am using the term "well-being" to refer to a state in which at least one of these elements is fulfilled. There is some reason to believe that well-being is a factor that ought to be prioritized for the dementia population. In this section I will describe some reasons that desire, pleasure, and happiness may contribute to a person's well-being and explain why well-being is important for people with dementia.

A framework of prioritizing well-being may be seen as a hedonistic approach to sex and persons with dementia. Hedonism typically considers pleasure to be the only thing that is "intrinsically prudentially good"¹⁴, though some "contemporary proposals [of hedonism] have

¹¹ Schroeder, "Desire."

¹² Leonard D. Katz, "Pleasure," *The Stanford Encyclopedia of Philosophy* (Winter 2016 Edition), ed. Edward N. Zalta, <https://plato.stanford.edu/archives/win2016/entries/pleasure/>.

¹³ Dan Haybron, "Happiness," *The Stanford Encyclopedia of Philosophy* (Fall 2011 Edition), ed. Edward N. Zalta, <https://plato.stanford.edu/archives/fall2011/entries/happiness/>; Different theorists have different conceptions of desire, pleasure, and happiness. These differences should not matter when it comes to considering a framework of well-being, however, it may be an area that could be researched in the future.

¹⁴ Maartje Schermer, "In search of 'the good life' for demented elderly," *Medicine, Health Care and Philosophy* 6 (2003): 36; Matthew Silverstein, "In Defense of Happiness: A Response to the Experience Machine," *Social Theory & Practice* 26, no. 2 (2000).

replaced [pleasure] with notions of enjoyment, happiness or satisfaction, and the absence of suffering.”¹⁵ From a hedonistic perspective, it is important to increase pleasurable and happy experiences and to avoid unpleasant ones. Part of de Lange’s book about the ethics of aging considers whether and/or how we can know what “the good” means for someone other than ourselves. In considering this question, de Lange says that a concept of the good life that focuses on increasing pleasurable experiences and decreasing suffering “seems to be a trustworthy criterion for judging the quality of life, especially that of elderly patients with dementia.”¹⁶ This is the primary reason that this framework, which includes desire, pleasure, and happiness, is being considered, namely, in order to improve people with dementia’s well-being by allowing them to pursue sexual acts. Although I am not a hedonist, there may be some reason to focus on pleasure and happiness when it comes to people with dementia.

In Western contexts, a person’s quality of life/well-being is considered to be important for all individuals—not just for people with dementia. If a person has a poor quality of life then measures are often put in place to either improve their quality of life and/or to end whatever is influencing their life’s poor quality. The importance of well-being is often used to support arguments for medical assistance in dying, for instance, where advocates suggest that a person’s quality of life and dignity is ultimately what matters (rather than, say, the number of years lived).¹⁷ From this perspective, if a person judges their quality of life to be unbearable and dying

¹⁵ Schermer, “In search of ‘the good life’ for demented elderly,” 36.

¹⁶ de Lange, *Loving Later Life*, 15.

¹⁷ Sometimes referred to as “physician assisted suicide” and/or “euthanasia”.

is their preferred option, then supporters of medical assistance in dying would say that their decision ought to be respected; quality of life matters.¹⁸

Prioritizing well-being and quality of life is laudable in some non-sexual decision-making contexts, and it serves as a justification in support of certain acts that may otherwise be seen as ethically illicit. An example of when well-being may be prioritized above other principles (e.g. beneficence, non-maleficence) was discussed during my applied philosophy placement. During a conversation with a social worker at a long-term care facility, the interviewee told me that ethical dilemmas sometimes arise for people with dementia when it comes to making choices about meals. She informed me that there have been cases of people with dementia wanting to *only* eat dessert. There have been other cases in which lifelong vegetarians have expressed a desire to consume meat. Although people in our society have the right to make risky decisions and/or to alter their values, the people in these cases are often unable to fully appreciate the risks and/or benefits that their decision(s) may pose when it comes to their health, values, or personal identity.

If people with dementia are unable to appreciate the potential consequences of their expressed desire(s), then other professionals and care providers are typically involved to help with decision-making processes (e.g. social workers, bioethicists, etc.). While a decision to only eat dessert would pose certain health concerns for anyone with or without dementia, the social worker informed me that many families and/or other providers will often honour and help satisfy the person with dementia's uninformed desire, such as allowing them to eat cake for breakfast. It is often the case that a person's desires, pleasure and/or happiness are sometimes seen as especially important from the perspective of promoting a good quality of life and well-being.

¹⁸ An additional justification that is often used in support of medical assistance in dying is the principle of autonomy, where a person's autonomous choice to end their life ought to be respected.

Given that dementia can result in a loss of interest in previously enjoyable activities, depression, severe mood swings and, ultimately, a poor quality of life, a person's well-being is often seen as more important even in comparison to other principles (e.g. autonomy and/or non-maleficence). While I recognize that the risks associated with allowing a person to only eat dessert and/or meat are different than those that may result from sexual allowances, the goal of honouring a person with dementia's well-being through satisfying desires, promoting pleasure, and enabling happiness is the primary message of this framework irrespective of the activity. So, if a person's sexual desires are satisfied, if they experience sexual pleasure, and/or if they gain a sense of happiness through sexual acts, then they may have a better quality of life, thereby potentially justifying their involvement to participate in such activities. This is at least part of the reason that Justice O'Connor allowed her husband to engage in a new relationship—his well-being was prioritized above other factors.

Advocates for people with disabilities (including dementia) and the elderly are starting to educate society about the fact that people of all ages with both physical and cognitive disabilities are sexual; they may want to partake in sexually pleasurable activities that can improve their quality of life. In his discussion of ageism, de Lange quotes Gilleard and Higgs, who say that a certain kind of imagery exists when it comes to some of society's eldest individuals. The imagery is one "where choice, autonomy, self-expression, and pleasure collapse into a silent negativity."¹⁹ This was discussed in Chapter One when we considered ageism as one of the intersectional challenges that may influence people with dementia. The pleasure that many elderly individuals may experience from engaging in certain activities, such as, perhaps, sexual

¹⁹ Chris Gilleard and Paul Higgs, "The Third Age and the Baby Boomers: Two Approaches to the Social Structuring of Later Life," *International Journal of Ageing and Later Life* 2, no. 2 (2007): 25; de Lange, *Loving Later Life*, 9.

acts (which is not discussed by de Lange) is ignored.²⁰ Recent anthologies such as McRuer's and Mollow's *Sex and Disability* also argue that people with disabilities are sexual. While their book mostly focuses on persons with physical disabilities, many of the themes relate to people with cognitive disabilities as well. The authors suggest that people with disabilities should be enabled to engage in sexual acts, at least in part, because they can contribute to happiness and well-being. Similarly, Perlin and Lynch argue that sexuality and pleasure is important to consider for people with cognitive impairments and mental illnesses.²¹ They think that our society ought to overcome certain stereotypes when it comes to people who are disabled. Legal theorist Margo Kaplan endorses a similar perspective, saying that "[s]exual pleasure is a good thing. It is a valuable source of happiness and personal fulfillment."²² Finally, in their discussion of sex and sexuality for LGBTQ people with disabilities, David Abbott and Joyce Howarth say that "the dominant agenda is still to prevent 'less bad sex' rather than supporting people to have relationships that are physically and emotionally satisfying."²³ This a problem when it comes to considering people with dementia since sexual acts can influence their well-being and quality of life.

Each of these theorists suggest that sexual pleasure is important for all individuals, and they advocate for people who are frequently stigmatized and excluded from these discussions, such as people with disabilities and the elderly. If people with dementia deserve to experience happiness and well-being (which, I suggest, they do) then the idea that they are sexual beings and

²⁰ de Lange discusses the importance pleasure, but he does not explicitly discuss sexual activities.

²¹ Perlin and Lynch, *Sexuality, Disability, and the Law: Beyond the Law Frontier?*

²² Kaplan, "Sex-Positive Law," 90.

²³ David Abbott and Joyce Howarth, "Still Off-Limits? Staff Views on Supporting Gay, Lesbian and Bisexual People with Intellectual Disabilities to Develop Sexual and Intimate Relationships?," *Journal of Applied Research in Intellectual Disabilities* 20, (2007): 117; Abbott and Howarth cite the following in this part of their discussion: David Thompson, "Is sex a good thing for men with learning disabilities?" *Tizard Learning Disability Review* 6, no. 1 (2001).

should be allowed to engage in pleasurable sexual acts is relevant; this is the reason that I refer to the above claims, namely, to highlight that sex and sexual pleasure are pertinent to all people.

In the subsequent sections I will consider what it would be like for someone with dementia to experience desire, pleasure, and happiness in accordance with this framework of prioritizing well-being. The framework is based on the *prima facie* notion that satisfying desires, pleasure, and happiness are all good things, where each element can independently contribute to a person's well-being. If none of these elements are satisfied then the likelihood that someone may experience undue harm (from engaging in undesired sex, for instance) may increase, which is why each of these elements is being considered.

3- Desire

Satisfying one's desires is, *prima facie*, a good thing. There may be exceptions to satisfying certain desires, such as a recovering alcoholic satisfying their desire for a drink, but overall the satisfaction of desires is typically positive.²⁴ Some desires are developed based on autonomous life choices, whereas others arise because of innate human needs. For instance, if a professor desires to publish an article in a prestigious journal and is successful, then the satisfaction of this desire would, indeed, be positive, and it may improve their well-being even if only temporarily. If a person is hungry and desires to eat, then giving them food would, similarly, contribute to their well-being in some kind of way. Turning to the sexual domain, then, if satisfying sexual desires for people with dementia can lead to some positive consequence(s) that may contribute to their well-being, then the satisfaction of this desire would be seen as

²⁴ We typically explain why satisfying certain desires is bad by referring to the effect that they have on the satisfaction of other desires. For instance, we might say that satisfying the alcoholic's desire for a drink is bad because it makes it more challenging for them to satisfy other central desires (e.g. autonomy, personal relationships, health, financial stability, etc.).

ethically licit in accordance with this framework of prioritizing well-being; in the absence of any complicating factors (e.g. the recovering alcoholic), satisfying desires is good. Satisfying a person's desire to engage in sexual acts may contribute to their well-being in two possible ways — either *just because* the desire was satisfied in and of itself, or because it creates a pleasurable experience and/or happiness, which also leads to well-being.

The type of sexual acts referred to in this dissertation involve two or more people. So, in order to satisfy the sexual desires of a person, accurate evidence of their desires must be determined.²⁵ One might claim, however, that it may be challenging for some people with dementia to explicitly communicate a desire to engage in sexual activities due to some of the symptoms of a dementia diagnosis, such as language and communication challenges. If some people with dementia are unable to explicitly communicate their desires then the potential for them to experience undue harm (and/or a lack of benefit and well-being) may increase since their desires may not be accurately understood and satisfied.

There may be one way to respond to the concern that some people with dementia may be unable to explicitly communicate their desire to engage in sexual acts. The method that may be helpful is a practice built on responding to assent. In his book on sexual consent, David Archard says that while consent is different than assent, they are closely related. He notes that “consent is essential agreement *to* something, [whereas] assent is essential agreement *with* something.”²⁶ Assent is typically used to describe a person's active willingness to pursue a particular act, specifically when they cannot provide informed consent. Assent requires the “dispositional

²⁵ Specifically, desires that require other people's involvement will need the desire to be understood in some way.

²⁶ Archard, *Sexual Consent*, 5

mental state of agreeing with [one's participation in a sexual act]"²⁷, whereas consent requires the cognitive capacity of knowing that one agrees to engage in a sexual act.

Respecting and responding to a person's assent is a practice that is already used in the medical domain for people who are incapable of providing informed consent, such as people with dementia, children, and/or persons who are incapacitated because of other means. I am proposing that the same practice of assent could be used in a framework of well-being for the sexual domain when it comes to gauging sexual desire. Some clinicians during my applied philosophy placement reinforced this practice, saying that assent can be a helpful way for people with dementia to contribute to their care and treatment decisions if they are incapable of providing informed consent. In these contexts, if a person with dementia expresses a willingness to participate in an activity or to pursue a particular treatment then this would be evidence of assent. Assent is important in the medical domain because it provides a way for healthcare providers and caregivers to respect the bioethical principle of respect for persons; they will often try to understand what a person wants, even if the person cannot comprehend relevant decision-making factors. As discussed previously, the principle of respect for persons involves respecting people's preferences and desires, even if they are unable to provide informed consent.

Since assent is already used in the medical domain as a way for people with dementia to communicate their desires and to have their desires (at times) respected, perhaps it could also be applied to the sexual domain. Sexual assent could be determined through a person's initiation of a sexual activity and/or through their active participation in response to a sexual request. Based on this practice of sexual assent, some of the individuals in Chapter Two would probably be seen as desiring to engage in sex since they expressed a willingness to participate, even if they had a minimal level of understanding about potential consequences. As communicated in one news

²⁷ Archard, *Sexual Consent*, 6.

article, Henry Rayhons's wife often initiated sexual requests, and sexual initiation would be classified as an expression of assent since it demonstrates one's desire to participate.²⁸ In the case of Karen Best, the nursing home informed Bob Best that Karen often instigated sexual activities, potentially because she desired to participate.²⁹ Although sexual assent may not necessarily mean that one is going to experience pleasure or happiness upon engaging in a sexual interaction, it could be indicative of at least some, if not many, individuals' desires to participate; one of the primary reasons that a person with dementia may assent to an activity is in order to experience something that they want.³⁰

It is possible that a person may desire to engage in sexual activities because of the physical contact it provides rather than for sexual pleasure itself. In his article "Plain Sex", Alan Goldman says that while "one may receive pleasure in a sex act from expressing certain feelings... sexual desire is essentially the desire for physical contact itself: it is the bodily desire for the body of another that dominates our mental life for more or less brief periods."³¹ His focus on the physical aspects of sexual desire is sometimes opposed by intentionalist conceptions of sexual desire. Intentionalist conceptions focus on the mental or intentional aspects of desiring something, where "understanding the interpersonal intentionality that occurs during sexual intercourse is essential."³² An intentionalist conception of sexual desire is not relevant to a framework of well-being since the symptoms of a dementia diagnosis may inhibit one from

²⁸ Belluck, "Sex, Dementia and a Husband on Trial at Age 78."

²⁹ Best and Trach, "What does consent look like when you have dementia?"

³⁰ For instance, a person with dementia may assent to eating a type of food by opening their mouth if they desire to eat/desire that type of food. They may not assent if they lack the desire.

³¹ Alan H. Goldman, "Plain Sex," *Philosophy and Public Affairs* 6, no. 3 (Spring 1977): 270-271.

³² Seiriol Morgan, "Sex in the Head," *Journal of Applied Philosophy* 20, no. 1 (2003): 2.

being cognitively aware of their sexual intentions (and the intentions of others). The type of desire that is relevant to this framework is based on physical desires — a person need not comprehend the intention of their desire in order for it to meaningfully represent something they want. According to this interpretation, a sexually desirable experience does not require a strong sense of self-awareness and reflective mental capacities, nor the desire to experience pleasure.

As mentioned, assent is used in the medical domain to help determine what a person with dementia would want/not want. However, in the medical domain, a person with dementia who assents to a treatment is not the final decision-maker (at least in most jurisdictions); other individuals have to officially consent on the person's behalf. For instance, suppose a person with dementia requires some type of surgical intervention in order to remove a malignant cancer tumor. In this case, assent would be a valuable way for the person with dementia to contribute to the decision about whether or not to receive surgery (they may agree to proceed even if they do not fully understand potential benefits/risks), however, a substitute decision maker would still need to provide informed consent on their behalf³³; this is a similar practice to advance directives (discussed in the previous chapter), where a person's advance medical directives still need to be interpreted and consented to by a substitute decision-maker in Canada.

Alternatively, I propose that a practice of assent for sexual activities would *not* require others to consent on a person's behalf. Under a framework of well-being, consent would be unnecessary. The purpose of sexual assent would be to help indicate a person's desire to engage in sex so that their desire can be satisfied; formal consent would not be required in addition to this practice. The reason that I diverge from the medical domain when it comes to obtaining consent from a substitute decision-maker is twofold. First, a person's desire to pursue a sexual

³³ *Substitute Decisions Act*, 1992, S.O. 1992, c. 30, <https://www.ontario.ca/laws/statute/92s30>.

activity is a deeply personal sentiment that others may be unable to understand and/or appreciate. Second, there may be barriers to involving other individuals when it comes to determining a person's sexual desire given that sex is a value-laden topic; this was discussed in the relational autonomy chapter. If a person with dementia desires to engage in sexual acts and if another party needs to consent in addition to the person's assent, then it seems plausible that the other party may impose their own values and possibly halt or alter the desired sexual activity. People have individual ideas about when and what kinds of sexual desires ought to be taken seriously, and this may be detrimental when it comes to satisfying the sexual desires of people with dementia.³⁴ The desire component of a framework of prioritizing well-being is meant to honour a person's desire irrespective of whether they have the capacity to autonomously understand the potential risks/benefits. Desire satisfaction may contribute to a person's well-being, especially if elements of pleasure and happiness are achieved as well.

There are two potential problems that ought to be considered when it comes to assent and sexual desire, however. The first problem is pertinent to women with dementia. In a previous chapter I introduced Emily Nagoski and her claim that women often have a *responsive desire* to sex. If a woman has a responsive sexual desire then she may not independently desire to engage in sexual activities and may not initiate sexual requests even though she may want to participate once a sense of sexual pleasure is awakened. Consequently, a woman may not communicate sexual assent until a sexual activity is underway. Responsive desires pose a challenge for some women since their desire to have sex may develop upon engaging in sex, which could consequently influence their sexual partner(s) to be too sexually aggressive on certain occasions

³⁴ For instance, Perlin describes the case of an owner of a care facility who only allows their residents to engage in sexual acts on Saturdays from 6:00-8:00pm because this is when he and his wife engage in sex (*Sexuality, Disability, and the Law: Beyond the Last Frontier?*, 2).

with the goal of awakening their responsive desire. For instance, suppose a woman typically had a responsive sexual desire prior to her dementia diagnosis and frequently wanted to participate in sex after being pursued by her partner. In this case, the woman's partner may decide to initiate and continue to pursue sexual acts with the woman with dementia, hoping to awaken her sexual desire. If the woman is unable to clearly articulate her preferences (or lack thereof) because of her dementia during a sexual engagement, then she may be more susceptible to experiencing harm if her partner continues to persist; a dementia diagnosis may make it more challenging to determine whether a person truly desires to engage in sex if they have a responsive sexual desire.

A second problem has to do with the fact that people are sometimes unaware of what they desire. de Lange says that “[d]esires can be disordered or wrongly expressed: I think I desire one thing, but I am actually longing for something else.”³⁵ This problem seems to reflect a lack of self-understanding and/or perhaps a difference between first and second-order desires. As we discussed in the preceding chapter, people with dementia may not know what their second-order desires are, and they may express first-order preferences that do not accord with their deeper desires. If a person with dementia has a lack of self-understanding because of their dementia diagnosis, then adhering to the act to which they assent may be ethically defensible from the perspective of prioritizing well-being, but it may be problematic if their expressed desire is not accurate. There is no obvious way to determine if a person's sexual assent reflects what they *actually* want (which is important if second-order desires matter).

4- *Pleasure*

Another way to contribute to a person's well-being may be to enable pleasurable sexual experiences. Pleasure is different from desire satisfaction since a person may experience pleasure

³⁵ de Lange, *Loving Later Life*, 15.

by pursuing activities that were not, initially, desired. Conversely, satisfying a sexual desire will not necessarily result in pleasure. A pleasurable experience may contribute to one's well-being by itself and/or it may cause one to be happy and consequently lead to well-being—this latter possibility will be described in the next section. If a sexual act may result in pleasure, and if this pleasure may result in increased well-being, then it would be a reason in favour of pursuing the sexual act from the perspective of this framework.

In *Sexual Consent*, Archard considers the question of why consent matters. He provides a few reasons for thinking that consent is important and one of these reasons is because of its direct relation to pleasure. He says:

In the case of sexual activity... it is plausible to think that individuals will normally only consent to what they believe they will find pleasurable and only find pleasurable what they consent to. In the first place, sex is mainly engaged in for its pleasure. Sex may be freely practised out of duty, habit, boredom, curiosity, defiance, revenge, the impulse to procreate, and, almost certainly, many more motives. But it is chiefly done for and in the expectation of pleasure... [t]he point is simply that it is unlikely that individuals should always voluntarily engage in sexual activity with no aim or hope of deriving pleasure from doing so.”³⁶

This idea may be oversimplified, but if it is at least somewhat true – if, in fact, pleasure is one of the primary reasons that people engage in sexual activities/desire to engage in sex – then it may be the case that a person with dementia who expresses a desire to have sex through assent is agreeing to participate for the same reason.

³⁶ Archard, *Sexual Consent*, 20.

Historically speaking, sexual pleasure has often been depicted as “a lesser good, a sin, a sickness, and a perversion”³⁷ rather than something that is valuable or ethically significant when it comes to well-being. The idea of sexual pleasure as a sin was influenced by Greek philosophical ideas that were upheld by the Roman Catholic Church, where “the assumption that the genitalia are an intrinsically inferior part of the body, much lower and less holy than the mind, the “soul,” the “heart,” or even the upper part of the digestive system (the status of the excretory organs is close to that of the genitalia)”³⁸ was prevalent. Rubin says that these ideas about sexual pleasure have acquired a life of their own; they “no longer depend solely on religion for their perseverance.”³⁹ Additionally, the medical model of sexuality (which developed in the late 18th and early 19th centuries) recognized non-procreative sex as a sign of sickness; the dangers and inappropriateness of engaging in certain types of sexual behaviors and at certain times of one’s life were emphasized and the potential for experiencing sexual pleasure was completely ignored.⁴⁰ During this point in time, it was thought that sexual activities may be only performed “within marriage for procreative purposes and if the pleasurable aspects are not enjoyed too much.”⁴¹ In the mid-20th century sexual pleasure was starting to be seen as relevant to sexual acts, but stigmatizing views around who should and should not engage in sex were still present. The idea that only certain people should be allowed to engage in sex reflects Rubin’s perspective of hierarchical sex acts, which we discussed in Chapter One.

³⁷ Mitchell S. Tepper, “Sexuality and Disability: The Missing Discourse of Pleasure,” *Sexuality and Disability* 18, no. 4 (2000): 286.

³⁸Rubin, *Deviations*, 148; Shrage and Stewart, *Philosophizing about Sex*, 74-75.

³⁹ Rubin, *Deviations*, 148.

⁴⁰ Tepper, “Sexuality and Disability: The Missing Discourse of Pleasure,” 286.

⁴¹ Rubin, *Deviations*, 148.

Mitchell Tepper describes a similar historical perspective about the medicalization and moralization of sex in his discussion on sex and pleasure. He says that “[t]he pleasurable aspect of sex in our culture has been largely ignored, vilified, or exploited.”⁴² The only cases in which sex is not ignored is when it is represented in the media, but in these cases “[s]exuality as a source of pleasure... is not readily recognized for populations that have been traditionally marginalized in our society... [such as] people who are older, who are larger, who are darker, who are gay, [and/or] who are mentally or physically disabled.”⁴³ Michael Gill makes similar claims where he aims to alleviate certain stereotypes that exist when it comes to sexuality and people with cognitive impairments. He says that both desire and pleasure are missing in sexual education materials, ignoring the potential importance of sexual pleasure altogether.⁴⁴ Sexual pleasure is rarely depicted as something that can contribute to well-being.

The topic of sex and pleasure also has a gendered component that ought to be taken into account. According to legal scholar Katherine Franke, sex and sexuality are typically considered in light of two principal concerns: dependency and danger.⁴⁵ She says that a primary focus in discussions about sex is to prevent women from engaging in dangerous or risky sexual acts. While the importance of harm prevention for marginalized and/or vulnerable populations (such as women) is indeed important to consider, Franke argues that it “risks making ‘women’s actual [sexual] experiences with pleasure invisible.’”⁴⁶ Although Franke does not discuss intersectional

⁴² Tepper, “Sexuality and Disability: The Missing Discourse of Pleasure,” 284.

⁴³ Tepper, “Sexuality and Disability: The Missing Discourse of Pleasure,” 285.

⁴⁴ Gill, *Already Doing It*, 79.

⁴⁵ Katherine M. Franke. “Theorizing Yes: An Essay on Feminism, Law, and Desire,” *Columbia Law Review* 101, no. 1 (January 2001): 182.

⁴⁶ Franke, “Theorizing Yes: An Essay on Feminism, Law, and Desire,” 200-201.

challenges for people with dementia specifically, a similar claim could potentially be made for all persons with dementia since they are a vulnerable population (though perhaps women with dementia may be especially pertinent when it comes to Franke's remarks). While it is important to protect people with dementia from harm, a primary focus on harm prevention could risk making pleasurable experiences invisible. This is something that we ought to consider given the importance of pleasure in relation to a person's well-being.

Franke thinks that a woman's right to enjoy her own body via sexual experiences is absent from many feminist legal arguments that encourage women to say "no" to sex; given the importance of pleasure and well-being, this is a problem. One theorist who makes this kind of argument is Catherine MacKinnon.⁴⁷ According to MacKinnon, "the social relation between the sexes is organized so that men may dominate and women must submit and this relation is sexual—in fact, is sex."⁴⁸ The inequity that exists amongst men and women both in and outside of the sexual domain influences much of MacKinnon's work, and it contributes to her thoughts on pleasure and sexuality. MacKinnon argues that "[d]ominance, principally by men, and submission, principally by women, will be the ruling code through which sexual pleasure is experienced."⁴⁹ From this perspective, gender norms are related to what counts (or ought to count) as a sexually pleasurable experience and female pleasure often involves submitting to the more powerful gender on the hierarchy (namely, males). MacKinnon says that "[b]ecause the inequality of the sexes is socially defined as the enjoyment of sexuality itself, gender inequality

⁴⁷ Franke, "Theorizing Yes: An Essay on Feminism, Law, and Desire," 200-201.

⁴⁸ Catharine A. MacKinnon, *Feminism Unmodified: Discourses on Life and Law* (Massachusetts: Harvard University Press, 1988), 3.

⁴⁹ MacKinnon, *Feminism Unmodified*, 7.

appears consensual.”⁵⁰ The reason that it may not actually be consensual, however, is because women do not have a choice to participate as equals. Rubin says that MacKinnon represents a view of traditional anti-sexual discourse.⁵¹ And insofar as dementia adds an additional element of vulnerability, then it may be important to ensure that women with dementia are protected from engaging in sex/sexual harms (specifically from perspectives such as MacKinnon’s).

In contrast to these perspectives, however, I argue that if sex can be a pleasurable activity, and if pleasure is at least sometimes relevant to a person’s well-being (which is almost certainly the case) then taking into account a person’s pleasure could be important when it comes to considering the ethics of sex for people with dementia. This perspective (and Franke’s view) supports the position of gay and queer legal theorists “who see these issues as about a “right to sex.””⁵² Rubin reinforces this perspective when she says that “[a] democratic morality should judge sexual acts by the way partners treat one another, the level of mutual consideration, the presence or absence of coercion, and the quantity and quality of the pleasures they provide.”⁵³ It is worth highlighting that while Rubin mentions the significance of sexual pleasure and the absence of coercion in this quotation, she does not explicitly discuss the importance of consent.⁵⁴

In order for pleasure to be a part of a framework of prioritizing well-being, we need to be able to determine whether someone with dementia is having a pleasurable sexual experience. Specifically asking someone with dementia whether they are experiencing pleasure may be

⁵⁰ MacKinnon, *Feminism Unmodified*, 7.

⁵¹ Rubin, *Deviations*, 172.

⁵² Franke, “Theorizing Yes: An Essay on Feminism, Law, and Desire,” 201.

⁵³ Rubin, *Deviations*, 154.

⁵⁴ I recognize that even though Rubin does not explicitly state that sexual consent should not be prioritized does not mean that she doesn’t think so.

possible in some circumstances, but it may be impossible for others because of certain dementia symptoms, as discussed above. For people who are unable to articulate whether they are experiencing pleasure, alternative methods of assessing pleasure may be helpful to consider. For instance, facial expressions may be a helpful way to gauge whether one is experiencing pleasure for long-time sexual partners who can reliably interpret their partner.

Another suggestion for determining if a person is having a pleasurable sexual experience may be to consider their physiological response(s) to sexual acts. If a person's body is responding to a sexual interaction in a certain way (e.g. through an erection and/or vaginal lubrication) then this may be one way to determine whether they are having a pleasurable experience, however, this is not consistently reliable. As stated by Nagoski, a person's body may naturally respond to a sexual interaction in a certain way, but this may not necessarily mean that a person is experiencing pleasure. For instance, a woman's vagina may naturally lubricate itself during a sexual activity and it is typically thought that this means that a woman is experiencing pleasure. However, Nagoski says that this is just her body's natural response to a sexual activity; it is not necessarily relevant to whether she is having a pleasurable experience.⁵⁵

Upon considering these different options, it seems that, again, perhaps the best way of determining whether a person is experiencing pleasure is by turning to a practice of assent; assent may be indicative of both desire (as discussed above) *and* pleasure. If a person is actively participating in a sexual act (as opposed to passively receiving sexual favours) then this may reflect their desire to continue participating *because* it is a pleasurable experience. Sexual assent may respond to some of the concerns regarding an individual with dementia's inability to explicitly communicate whether they are having a pleasurable experience. Moreover, it not only

⁵⁵ Nagoski, *Come As You Are*, 192.

considers a person's physiological response to sex as a determination of pleasure, but also whether a person is actively expressing a willingness to participate. This may be a more reliable way to determine whether a person with dementia is experiencing pleasure, and consequently, improved well-being.⁵⁶

5- *Happiness*

A framework of prioritizing well-being is motivated by the idea that well-being ought to be prioritized above other considerations when it comes to sex, and happiness is another factor that is *prima facie* relevant to well-being.⁵⁷ It seems possible that sexual activities may cause happiness in at least one of three ways. First, if a person satisfies a desire to engage in sexual activities and/or experiences sexual pleasure, then it may constitute happiness. It also seems possible that a person who is in a long-term relationship may agree to participate in sex *not* because they desire it or experience pleasure, but solely because their partner wants to have sex with them, and satisfying their partner's desire may make the person happy. A person may also feel happy after a sexual interaction just because of the satisfaction they gained from being close to another person — not necessarily because of any satisfied desire or pleasure.⁵⁸

There has been a minimal amount of empirical research completed on the idea that sex may cause happiness, so it is difficult to know which (if any) of the above three suggestions may most accurately reflect a link between sex and happiness in all circumstances. Three studies, however, do suggest that this link exists. In 2004, a study was done on 909 employed women

⁵⁶ While sexual assent may be a more reliable way to determine if a person is experiencing sexual pleasure, I recognize that the potential to misinterpret a person's willingness to participate in sex is a risk. This kind of potential risk will be considered in the subsequent chapter.

⁵⁷ Daniel Kahneman et al., "Toward National Well-Being Accounts," *American Economic Review* 94, no. 4 (2004): 429-434.

⁵⁸ Doll, *Sexuality and Long-Term Care*, 4 and 104.

who retrospectively rated sex as the activity that produced the most enjoyment and happiness (in a list of nineteen activities).⁵⁹ A similar study was completed by economists Blanchflower and Oswald. Their study explored the link between sex and happiness by surveying about 16,000 randomly selected Americans. The main finding of their results was that sex is, indeed, linked with happiness as the dependent variable: “[t]he more sex, the happier the person.”⁶⁰ Moreover, they say that “[t]he effect of sex on happiness is statistically well-determined, monotonic and large”⁶¹ for both men and women, and for people both under and over forty years of age. In their analysis, the economists also note that “individuals who have no sexual activity are less happy than average.”⁶² A similar study to Blanchflower’s and Oswald’s was completed by Zhiming Cheng and Russell Smyth on 3800 adults in China. Cheng and Smyth followed the same methodology as Blanchflower and Oswald and their results were remarkably similar. Cheng and Smyth found that people who frequently engage in better quality sex (namely, pleasurable sex) and with one primary partner are more likely to be happy. Furthermore, they found that “having unwanted sex or having sex simply to satisfy one’s partner is associated with lower happiness.”⁶³

⁵⁹ Kahneman, “Toward National Well-Being Accounts,” 432.

⁶⁰ Blanchflower and Oswald, “Money, sex and happiness: an empirical study,” 400.

⁶¹ Blanchflower and Oswald, “Money, sex and happiness: an empirical study,” 411; the authors do note, however, that the results may be influenced by individuals’ undetectable biases, the desire to boast about their sex lives, discomfort speaking about sex, etc.

⁶² Blanchflower and Oswald, “Money, sex and happiness: an empirical study,” 400.

⁶³ Zhiming Cheng and Russell Smyth, “Sex and Happiness,” *Journal of Economic Behavior and Organization* 112, (2015): 26; the authors’ latter point which says that having sex to please one’s partner lowers happiness shows that my second proposed reason that sexual acts may result in happiness (namely, for the purpose of pleasing one’s partner) may be wrong. Also, similar to Blanchflower and Oswald, the authors note that the results may be influenced by biases.

People with dementia who have language and communication challenges may be unable to describe whether they are happy after engaging in sex — they may not be able to complete a version of the surveys that were used in the studies. There is no reason to believe, however, that the link between sex and happiness would differ when it comes to people with dementia or other cognitive impairments. Based on the available studies, it seems plausible that if a person with dementia satisfies a sexual desire and/or experiences sexual pleasure (as determined by a practice of assent), then we may be able to infer that they will experience happiness as well.

6- A Practical Example

The Hebrew Home at Riverdale (hereafter referred to as the Hebrew Home) shows us how a framework of prioritizing well-being may work in practice when it comes to sex. The Hebrew Home realizes that many of their residents (both with and without dementia) are sexual beings who may be willing and wanting to engage in sex and other intimate activities upon entering into this new phase of their life. In order to mitigate any challenges that may result from residents engaging in sexual acts (such as the potential to experience undue harm), the nursing home developed a sexual expression policy in 1995.⁶⁴ It was most recently revised in 2013.⁶⁵ The development of this policy was prompted by a scenario when a nurse walked into a room where two residents were having sex. According to a news report, “[w]hen the nurse asked Mr. Reingold [the president and chief executive of the nursing home] what to do, he told her, “Tiptoe

⁶⁴ Hu, “Too Old for Sex? Not at This Nursing Home.”

⁶⁵ Robin Dessel and Mildred Ramirez, “Policies and Procedures Concerning Sexual Expression at the Hebrew Home in Riverdale,” April 2015, accessed May 28, 2018, <http://static1.squarespace.com/static/5520af09e4b0c878b5733095/t/56328f20e4b04afbbe92827d/1446154016232/sexualexpressionpolicy.pdf>.

out and close the door behind you.”⁶⁶ It is unclear whether either or both of the residents in this scenario were diagnosed with dementia.

The Hebrew Home’s sexual expression policy says that caring for the social needs of their residents both with and without dementia “carries with it a responsibility to uphold their personal and sexual choices.”⁶⁷ The Home recognizes that residents have a right to engage in sexual activities with other residents and/or with visitors. However, they also note that their residents can only engage in sexual activities insofar as they can express consent, which, they say, can be given via *affirmative action*.⁶⁸ This understanding of consent seems to encompass a practice of assent since consent typically requires the capacity to understand the nature and potential consequences of a particular decision (which many people with dementia may not have). The policy says that if there is any question about whether a resident can consent to sex due to factors such as dementia, then the Hebrew Home’s clinical staff complete an assessment. The staff are required to follow the Hebrew Home’s “Assessing Consent to Sexual Activity” guidelines in order to maintain as much objectivity as possible. The guidelines prompt staff to ask various questions in order to gauge a resident’s affirmative agreement to engage in sexual acts. Some of these questions are: “Does your sexual partner make you happy?”, “Do you enjoy sexual contact?”, “Do you know what it means to have sex?”, “What would you do if you wanted it to stop?”, “Was and is intimacy important in your life?”, “What brings happiness or fulfillment in your day?”⁶⁹ Alongside asking these questions, staff are required to consider

⁶⁶ Hu, “Too Old for Sex? Not at This Nursing Home.”

⁶⁷ Dessel and Ramirez, “Policies and Procedures Concerning Sexual Expression at the Hebrew Home in Riverdale.”

⁶⁸ Dessel and Ramirez, “Policies and Procedures Concerning Sexual Expression at the Hebrew Home in Riverdale.”

⁶⁹ The Weinberg Center and the Hebrew Home at Riverdale, “Abuse or Intimacy: Older Adult Sexuality,” 2011, accessed March 28, 2018,

additional factors, such as: facial expressions and body language (specifically if a resident is unable to verbally articulate their responses); the resident's emotion and mood before and after a sexual act; the nature of the relationship (e.g. is it monogamous?); past and present relationships; the responsibility to respect the sexual choices of older adults and; the potential impact that third party values may have on the assessment process.⁷⁰

The Hebrew Home's policy on sexual expression and their corresponding guidelines are meant to determine whether a person with dementia can *consent* to a sexual interaction. As mentioned above, however, the Hebrew Home's requirements for determining consent seem to be less stringent than other frameworks of consent (e.g. those discussed in Chapter One) since a person may not have the capacity to understand the potential risks and benefits of engaging in a sexual interaction. Moreover, a person's capacity may fluctuate with a dementia diagnosis. A person with dementia may be entirely lucid when deciding to have sex on one occasion and not on another. The Hebrew Home seems to consider a person's desire, pleasure, and happiness (as communicated through a practice of assent) as relevant to their assessment—this is similar to my proposed framework of prioritizing well-being. Although other nursing homes and organizations may inhibit sexual activities from occurring when it comes to people with dementia because of their inability to consent to sex in accordance with typical frameworks, the Hebrew Home seems to have expanded what it means for residents to consent in order to recognize factors such as desire, pleasure, happiness and, ultimately, well-being, as pertinent. The policy and the guidelines of the Hebrew Home do not specify precisely what is done if a person with dementia *cannot* recall prior sexual values and/or their partners (such as a spouse) upon being asked. But

<https://static1.squarespace.com/static/5520af09e4b0c878b5733095/t/56329028e4b0eaf99e2c2b71/1446154280079/sexualconsentguidelines.pdf>.

⁷⁰ *The Weinberg Center and the Hebrew Home at Riverdale*, "Abuse or Intimacy: Older Adult Sexuality."

based on their focus of enabling sexual expression and sexual well-being for their residents, there is reason to believe that if a person expresses a desire to engage in sexual acts then they would be allowed to proceed irrespective of potential conflicts. Perhaps the Hebrew Home would try to mitigate potential conflicts (e.g. disapproval from a resident's spouse) in order to enable sexual expression, though this is not clear.

One of the differences between the Hebrew Home's sexual consent policy and my proposed framework is that the Hebrew Home suggests that *consent* is prioritized—consent is required by New York's Penal Law and the Hebrew Home provides people with the opportunity to meet this legal requirement; they seem to offer some support that is similar to my account of supported decision-making (which we discussed in Chapter Three).⁷¹ According to my framework of well-being, however, well-being would be prioritized irrespective of whether a person can consent. I suggest that satisfying desires, pleasure, and happiness can contribute to a person's well-being, and well-being is the determining factor of whether a sexual act is ethically licit.

7- *Conclusions*

This chapter introduced a framework of prioritizing well-being as a way to approach the topic of sex and dementia. Since many people with dementia may have limitations when it comes to their capacity to consent to sex, this chapter aimed to honour a person with dementia's well-being by satisfying desires, sexual pleasure, and happiness.

In order to determine whether a person with dementia desires to engage in sexual acts, a practice of responding to a person's assent was proposed. Assent is used in the medical domain

⁷¹ ypdcrime.com, *New York State Law Penal Law: Consolidated Laws of New York's Penal Code*, s. 130.05, <http://ypdcrime.com/penal.law/article130.htm#p130.05>.

so that people who are unable to make their own treatment decisions can be included in the decision-making process. Assent is a practice in which a person expresses some form of willingness or desire to participate in an activity even if they are unable to understand and critically reflect upon potential risks and benefits. Assent may be helpful in the sexual domain so that a person's desire to engage in sex can be appropriately gauged. Assent may also be helpful when it comes to the second factor discussed in this chapter, namely, for evidence of pleasure. If a person assents to continue to participate in a sexual activity (either after initiating sex or after being pursued) then there is some reason to believe that this may be because they are having a pleasurable experience. Finally, empirical evidence suggests that sex leads to happiness for people who engage in wanted (as opposed to unwanted) sex that is pleasurable. Insofar as both sexually desirable and sexually pleasurable experiences are relevant to a person's happiness, then these two factors (as expressed via assent) may help to ensure that a person's happiness is honoured, which may consequently lead to increased well-being.

The final section of this chapter described the sexual consent guidelines of the Hebrew Home at Riverdale. The Hebrew Home developed sexual *consent* guidelines for their residents both with and without dementia, however, their guidelines seem to require a practice of assent that is similar to my proposed framework. The overall goals of the Hebrew Home are to prioritize well-being and to prevent people from experiencing undue harm, though they say that consent is required, which is different than my framework.

Overall, this chapter was based on the idea that honouring a person with dementia's well-being is important to approaching cases of sex and dementia. A framework that prioritizes well-being may be seen as a counterintuitive approach to sex given the significance of consent in Western societies, but it is one that ought to be considered if it is important to promote well-

being for people with dementia.⁷² The following chapter will offer an evaluation of this framework and the previous frameworks proposed.

⁷² I am not suggesting that conceptions of sexual consent for people *without* dementia need to be reconsidered and I recognize that there are some potentially serious consequences of this framework that will need to be taken into account. I consider some of these possible consequences in Chapter Six.

Chapter 6

An Open-Ended Evaluation

Before continuing onto this chapter, I will briefly describe my project thus far. In Chapter One, I explained why sexual consent is seen as legally and morally significant in Western liberal contexts, described current models of sexual consent (e.g. “‘no’ means no”), and outlined some intersectional challenges. In Chapter Two I explained that people with dementia are sexual beings and introduced five cases to show that current models of consent are often unhelpful. In Chapters Three, Four, and Five I presented three different frameworks as ways to approach cases of sex and dementia. Chapter Three described a framework of relational autonomy and supported decision-making, Chapter Four introduced a framework of advance sexual consent, and Chapter Five discussed a framework of prioritizing well-being.

The purpose of this chapter is to illustrate some lessons that can be learned from each of the frameworks and to give a proposed method for approaching cases of sex and dementia moving forward. In order to complete this task, I initially build on some of the positive and negative considerations of each of the frameworks. Given that each of the frameworks introduce various factors that need to be considered, I argue that one framework is not necessarily going to be better/more ethically defensible than the others in every context; different situations will need to be approached differently. In the next part of the chapter I argue that some kind of integrated framework may be helpful so that various factors can be thoughtfully considered on a case-by-case basis. I introduce Beauchamp and Childress’s process of weighing and balancing as part of this integrated approach; their approach to ethical dilemmas involves weighing and balancing conflicting principles and norms in order to determine an ethically defensible decision. I suggest that a similar process ought to be used to consider the many factors that are relevant to cases of

sex and dementia. In the final part of this chapter, I consider different scenarios involving sex and dementia and show how relevant considerations and norms may be weighed and balanced.

1- The Three Frameworks: Positive and Negative Considerations

Relational Autonomy and Supported Decision-Making:

The first framework that I introduced to approach cases of sex and dementia was a framework of relational autonomy and supported decision-making. This framework focused on enabling autonomous decision-making for people with dementia by providing decision-making support. I initially introduced Boni-Saenz's cognition-plus approach to support sexual decision-making and then Davy's framework. Both accounts focus on enabling autonomous decisions with support networks. The ultimate framework that I proposed expanded on Boni-Saenz's and Davy's approaches by suggesting that consistent decisions, and decisions that do not conflict with other expressed decisions and values, ought to be part of autonomous sexual decision-making for people with dementia.

One of the positive considerations of this framework is that people with dementia are seen as capable of making autonomous decisions; this responds to the common and problematic idea that people with dementia are unable to make autonomous choices. If people with dementia can make autonomous sexual decisions with support, and if their support networks prevent them from experiencing undue harm, then this seems to respond to some of the primary arguments that are often used to prevent people with dementia from engaging in sex.

There are also a few potential challenges with this framework. One challenge is the possibility of support networks imposing their own sexual preferences or values onto a person with dementia, thereby defeating the purpose of enabling autonomous decision-making. Another

challenge is that a relational autonomy framework may not adequately respond to some of the challenges associated with some intersectional identities. For instance, if a woman with dementia holds an adaptive sexual preference because of the way that she was socialized to behave, and if adaptive preferences are non-autonomous (as discussed in Chapter Two), then enabling this kind of decision would fail to be relationally autonomous—and if autonomous decisions are those which ought to be respected as per the principle of autonomy, then these kinds of decisions would be moot. The final challenge discussed in regard to this framework is that relational accounts focus on enabling present sexual decisions. The framework does not consider prior autonomous sexual preferences as relevant; this could pose a challenge for people who had strong sexual preferences or values prior to dementia, especially when it comes to respecting the person's identity and dignity.

Advance Sexual Consent:

The second framework that I introduced in Chapter Four was a framework of advance sexual consent. This framework considered the possibility of allowing people to express their sexual preferences in advance sexual directives, similar to advance directives that are used in the medical domain. Boni-Saenz's consensus of consents model was introduced as a part of this framework. The model suggests that a person with dementia could be seen as consenting to sex if their current sexual volitions match their prior sexual preferences. I expanded on this account and proposed that a hybrid framework may work best for people who cannot affirmatively agree to participate. A hybrid account considers a person's prior autonomous decisions (as communicated in advance directives) through a consensus of consents, yet a substitute decision maker would assist with any questions of interpretation.

The positive and negative considerations of this framework are similar to those that are frequently outlined when it comes to advance directives in general. One positive consideration is that it allows people to communicate any strong sexual preferences that are critical to one's identity. Moreover, it enables people with dementia to (indirectly) consent to sexual activities without the significant involvement of others. If a person with dementia communicated that they want to have sex with their spouse in an advance directive, and if they express a corresponding interest after a dementia diagnosis, then they would be seen as consenting (at least according to Boni-Saenz's account and a hybrid model).

One potential challenge with this approach is that advance sexual directives assume that a person with dementia is the same person as their pre-dementia self; it fails to adequately consider the possibility of changing preferences and/or identities. A second challenge is that if the goal is to enable autonomous sexual decision-making while at the same time preventing people from experiencing harm, then certain sexual decisions may be classified as problematic (or at least risky) from the perspective of non-maleficence.¹ For instance, if a person expresses an interest in BDSM activities, then the likelihood of them experiencing harm (if they cannot remember their safe word, for instance) with a dementia diagnosis may be quite high.

Prioritizing Well-Being:

The third framework I introduced prioritized well-being. This framework considered a person with dementia's current sexual interests as important insofar as they were likely to contribute to a person's well-being; well-being was prioritized above conceptions of autonomy, consent, and/or the capacity to communicate preferences that align with prior sexual decisions.

¹ Preventing harm from happening accords with a key bioethical principle, namely, a principle of non-maleficence.

Three factors were introduced as relevant to well-being: (1) satisfying sexual desires; (2) pleasure; and (3) happiness.

The primary positive consideration of this framework is that it focuses on a person's well-being and happiness, which is especially important for people with dementia. People with dementia are often unable to participate in many activities that they previously enjoyed. Consequently, their quality of life often diminishes. Also, developing and maintaining relationships may be challenging with dementia. There may be times when a person with dementia may not remember whether they are in a monogamous relationship and/or with whom (e.g. the case of Justice O'Connor).

There are some challenges with this framework, the first of which relates to desire and responsive sexuality. If a person has a responsive sexuality (which affects women more than men) then they will *not* have a sexual desire without being pursued by a potential sexual partner. If someone tries to have sex with them and if they cannot explicitly dissent, however, then they may be at risk for experiencing undue harm; the reason that they may be unable to express dissent could be because of their dementia and/or because of socialized deference, which we discussed in Chapter Three. Implementing an ongoing assent requirement (communicative sexuality) may help to mitigate these challenges, but the challenges are still worth mentioning since they could influence a person's well-being.

2- Considering an Integrated Framework

It is challenging to determine which, if any, of the above frameworks is ultimately best when it comes to approaching cases of sex and dementia. There are many factors that need to be considered for each of the frameworks and different factors may be more pertinent for different

situations; it seems unlikely that one framework will be more ethically defensible than the others in every context. In order to approach cases of sex and dementia moving forward, I suggest that an integrated framework may be helpful to consider.

An integrated framework would involve weighing and balancing the different considerations and norms that are relevant to a particular case. The three frameworks introduced some of the factors that will need to be weighed and balanced on a case-by-case basis according to an integrated approach, such as autonomous decision-making, protecting persons with dementia from undue harm, enabling well-being, etc.

In order to manage cases of sexual activities for people with cognitive impairments (which is the focus of their book), Perlin and Lynch suggest the concept of balancing. They say that “it is necessary to balance the cognitively impaired individual’s sexual expression with the societal interest of prohibiting illegal sexual conduct.”² Perlin and Lynch recognize sexuality as an important part of individuals’ well-being, alongside the need to protect vulnerable populations from harm. Evelyn Tenenbaum also expresses this concept of balancing in her article about sex in nursing homes. She says that nursing home staff must “provide enough supervision to protect against rape and sexual abuse while not oversupervising so that sexual intimacy is stifled.”³ Similar to people with cognitive impairments, people with dementia are a vulnerable population that may be interested in sexual acts. The combination of sexuality and vulnerability motivates the need to balance one’s right to sexual expression with the need to protect one from harm in many cases, and there are different principles and norms that will also be relevant to cases of sex and dementia.

² Perlin & Lynch, *Sexuality, Disability, and the Law: Beyond the Law Frontier?*, 79.

³ Tenenbaum, “To Be or to Exist: Standards for Deciding Whether Dementia Patients in Nursing Homes Should Engage in Intimacy, Sex, and Adultery,” 688.

In order to consider an integrated approach of weighing and balancing for cases of sex and dementia, I propose using Beauchamp and Childress's method as a starting point. Beauchamp and Childress talk about weighing and balancing conflicting factors in the bioethics domain and their approach may help to determine how some of the norms and principles that come up in the three frameworks can be considered. In *The Principles of Biomedical Ethics*, Beauchamp and Childress outline the "four-principles approach" to biomedical ethics, often referred to as principlism.⁴ Principlism is composed of four primary principles: respect for autonomy, beneficence, non-maleficence, and justice. These principles/moral norms derive from the common morality ("the set of universal norms shared by all persons committed to morality"⁵) and they are meant to guide ethical practices in healthcare contexts, including research, public health, and health policy development. One of the objections to principlism, however, is that there are sometimes situations in which "moral obligations demand or appear to demand that a person adopt each of two (or more) alternative but incompatible actions"⁶ which is what Beauchamp and Childress define as a moral dilemma. One example of a moral dilemma is a person who steals food from a grocery store in order to feed their starving family.⁷ This is a dilemma since the ethical permissibility of this action could be justified by principle of beneficence (helping their family) and it could be seen as unjust since it is unfair to the storeowner and potentially causes harm (conflicting with the principles of non-maleficence and

⁴ Beauchamp and Childress, *Principles of Biomedical Ethics*, 25.

⁵ Beauchamp and Childress, *Principles of Biomedical Ethics*, 4; they say that the common morality is "a product of human experience and history and it is a universally shared product."

⁶ Beauchamp and Childress, *Principles of Biomedical Ethics*, 11.

⁷ Beauchamp and Childress, *Principles of Biomedical Ethics*, 11.

justice).⁸ I regularly witness moral dilemmas as a healthcare ethicist since there are often conflicting factors that are relevant to addressing complex medical cases. Similarly, there are multiple ways to argue in support of or against different approaches to sex and dementia in relation to specific cases (and even for/against the question of whether people with dementia ought to engage in sex).

In response to moral dilemmas, Beauchamp and Childress say that the four principles can guide the development of more specific rules. For instance, the principle of autonomy may be used to justify a substantive rule like: “Respect the autonomy of incompetent patients by following all clear and relevant formulations in their advance directives.”⁹ The process of specifying principles to develop specific rules is called “specification”, and rules can be specified an indefinite number of times in order to qualify a particular moral norm. For instance, the above rule about advance directives could be further specified to apply to cases when an advance directive might lead to prolonged suffering; the rule might be specified to say “[r]espect the autonomy of incompetent patients by following all clear and relevant formulations in their advance directives [unless the patient is experiencing prolonged and undue suffering].”¹⁰ We might subsequently realize, however, that some people may need to suffer for a long period of time in order to eventually receive some benefit, and so this rule may need to be further specified, etc. Beauchamp and Childress refer to this process as “progressive specification”.¹¹

In order to approach dilemmas involving more than one principle, Beauchamp and Childress introduce a process of weighing and balancing. While specification involves

⁸ Beauchamp and Childress, *Principles of Biomedical Ethics*, 11.

⁹ Beauchamp and Childress, *Principles of Biomedical Ethics*, 14.

¹⁰ Beauchamp and Childress, *Principles of Biomedical Ethics*, 14.

¹¹ Beauchamp and Childress, *Principles of Biomedical Ethics*, 17.

developing specific rules based on specific principles, a process of weighing and balancing is concerned about how different moral norms ought to be weighed and prioritized in comparison to other norms in particular circumstances. Beauchamp and Childress say that “principles must be balanced and specified so they can function in particular circumstances. It is no objection to moral norms that, in some circumstances, they can be justifiably overridden by other norms with which they conflict.”¹² They refer to W.D. Ross’s distinction between *prima facie* and *actual* obligations to help make their point about weighing and balancing principles. Following from Ross, Beauchamp and Childress note that “[a] *prima facie* obligation must be fulfilled unless it conflicts with an equal or stronger obligation... [o]bligations and rights always constrain us unless a competing moral obligation or right can be shown to be overriding in a particular circumstance.”¹³ So, if a particular action is justified by the principle of autonomy and if there are no competing principles, then the action must be followed. If, however, two or more conflicting actions can be justified by different *prima facie* principles/obligations, then a person ought to weigh competing *prima facie* obligations — “[w]hat agents ought to do is, in the end, determined by what they ought to do all things considered.”¹⁴

Balancing is based on the weights and strengths that are given to moral norms in particular circumstances; a process of balancing “consists of deliberation and judgment about these weights and strengths.”¹⁵ In order to describe how a process of balancing works, Beauchamp and Childress give the example of a physician who encounters an emergency with a patient. In order to take care of the emergency, the physician will need to extend her work day

¹² Beauchamp and Childress, *Principles of Biomedical Ethics*, 15.

¹³ Beauchamp and Childress, *Principles of Biomedical Ethics*, 15.

¹⁴ Beauchamp and Childress, *Principles of Biomedical Ethics*, 15.

¹⁵ Beauchamp and Childress, *Principles of Biomedical Ethics*, 20.

and abandon her promise to take her son to the library. The physician deliberates about what she should do by weighing and balancing different principles and options in light of her current circumstance: she considers her ethical obligations as a physician (e.g. to help her patients, prevent harm, etc.) while at the same time considering the extent of the emergency, whether someone else may be able to handle the emergency, how this may impact her patient, what it would mean to break a promise with her son, etc. After weighing and balancing each of these options, she judges her professional obligations to her patient to override taking her son to the library. Her justificatory reason may be “that a life hangs in the balance and she alone may have the knowledge to deal adequately with the circumstances.”¹⁶ Although she may not feel good about cancelling on her son, her action is justified in this particular circumstance, all things considered. In most moral dilemmas, many considerations need to be weighed and balanced against one another—it is rarely the case that a process of specification will, alone, be able to resolve all dilemmas.¹⁷ A process of weighing and balancing will take many factors into account.

Beauchamp and Childress say that a process of balancing and weighing principles should involve well-reasoned arguments. A rigorous process of weighing and balancing that is based on “practical astuteness, discriminating intelligence, and sympathetic responsiveness”¹⁸ will help to assign relevant weights to the different possible options so that a final decision can eventually be made. Beauchamp and Childress realize, however, that while a process of weighing and balancing should not be influenced by personal intuitions and preferences, these elements will often contribute to a decision-making process. In order to mitigate the possibility of personal

¹⁶ Beauchamp and Childress, *Principles of Biomedical Ethics*, 20.

¹⁷ Beauchamp and Childress, *Principles of Biomedical Ethics*, 20; Beauchamp and Childress say that a person who has to decide between two or more competing actions may experience “moral regret” upon choosing one act over another, even if they pursue the morally best act (16).

¹⁸ Beauchamp and Childress, *Principles of Biomedical Ethics*, 20.

preferences, intuitions, and biases skewing the most ethically defensible choice, they propose adhering to the following six conditions:

1. Good reasons can be offered to act on the overriding norm rather than on the infringed norm.
2. The moral objective justifying the infringement has a realistic prospect of achievement.
3. No morally preferable alternative actions are available.
4. The lowest level of infringement, commensurate with achieving the primary goal of the action, has been selected.
5. All negative effects of the infringement have been minimized.
6. All affected parties have been treated impartially.¹⁹

Adhering to these conditions will help to encourage a well-reasoned process of weighing and balancing in order to determine the most ethically justifiable act.

The authors realize that a process of balancing may not necessarily lead to the same conclusion for all parties involved even after following the six conditions. This is referred to as a moral disagreement. Moral disagreements may occur because people: (1) weigh the same factors differently and/or (2) disagree about the facts (e.g., about the amount of benefit/suffering that an act will cause and/or (3) disagree about the principles that ought to be considered, etc.²⁰ Moral disagreements are bound to occur amongst well-reasoned parties and Beauchamp and Childress say that one should feel comfortable defending one's decisions while at the same time evaluating and considering other views.

¹⁹ Beauchamp and Childress, *Principles of Biomedical Ethics*, 23.

²⁰ Beauchamp and Childress, *Principles of Biomedical Ethics*, 24.

A few factors may be especially important when it comes to weighing and balancing some of the norms and principles of the three frameworks. For instance, the stage of a dementia diagnosis may be relevant to deciding how much a person's autonomy ought to be considered. A person with mild-to-moderate dementia may be able to communicate autonomous decisions with support, and if an adequate support network is available then perhaps enabling autonomy and weighing this principle accordingly would be appropriate; it would provide the person with an opportunity to alter previous sexual preferences and communicate new values, desires, wishes, etc. If, however, a person is unable to communicate autonomous decisions, then perhaps their past autonomous preferences and/or their current well-being should be given more weight. Furthermore, the principle of non-maleficence might become especially significant when a person's dementia progresses since they may be unable to protect themselves from undue harm. Some of the other norms and principles that may be relevant to the frameworks are: dignity, beneficence, well-being (which incorporates desire satisfaction, pleasure, happiness), precedent autonomy, etc. These principles will need to be weighed and balanced in light of a person's dementia diagnosis and specific life circumstances.

In the subsequent section I will offer some examples of how a process of weighing and balancing may work. The process of weighing and balancing below is meant to serve as a general example—I am not making any conclusive remarks about necessarily whether and/or what conclusion would be best or most likely agreed upon for similar real-life scenarios since every case will have individual aspects that will be pertinent to the process. I will be using some of the principles mentioned above in considering the cases. The purpose of this section is to demonstrate how a process of weighing and balancing may be helpful for approaching situations of sex and dementia on a case-by-case basis; it is an example of an integrated approach.

3- A Process of Weighing and Balancing

Weighing and Balancing—the Rayhons case:

I have discussed the Rayhons case a few times throughout this dissertation. Recall that Henry Rayhons was accused of sexual assault after having sex with his wife in a nursing home because his wife had dementia and could not consent in traditional ways. Let's suppose that after discovering Henry Rayhons and his wife having sex, the nursing home caregivers asked themselves how they should approach this situation and similar future circumstances; they wanted to proceed in an ethically defensible manner.

According to my proposal, the caregivers should approach this case by undergoing a process of weighing and balancing; they should consider Beauchamp and Childress's primary bioethical principles and the other principles and norms that were introduced by three frameworks.

As mentioned before, there is widespread agreement in bioethics that if a person is able to make an autonomous decision then that choice ought to be respected.²¹ It is also commonly agreed that capable persons have the right to make seemingly risky decisions based on their preferences, values, and beliefs. If, based on her stage of dementia, Donna Rayhons is capable of making an autonomous choice with support, and if she has a support network (e.g. Henry Rayhons), then perhaps that support ought to be provided for sexual decision-making given the significance of autonomy. It may also be important to weigh and balance a principle of non-maleficence with that of autonomy, especially since Donna is a part of a vulnerable population who may be more likely to experience undue harm. So, even if Donna is able to make an autonomous choice, the principle of non-maleficence would still need to be given significant

²¹ This typically involves being able to comprehend potential benefits and consequences of a particular decision.

weight. If Donna is unable to make an autonomous choice and/or unable to fully appreciate the potential consequences of her autonomous sexual decision(s) then a principle of non-maleficence would need to be weighed more significantly. In order to prevent Donna from experiencing harm, ensuring that she assents to sex before and during a sexual encounter may be helpful. Also, we might want to ask whether Donna's past sexual preferences align with her current preferences. If yes, and if she expresses sexual assent, then there might be an even lower risk of her experiencing undue harm and a better reason to allow her to engage in the sexual acts to which she assents.

It may also be helpful for the caregivers in this case to consider a principle of justice in terms of whether Donna has a *right* to engage in desired sex with her husband. Would it be unfair to disallow Donna from participating in an act that she wants to pursue? If she deserves to participate in a sexual interaction with her husband even if she cannot consent in typical ways, then preventing her participation may be seen as a type of injustice (and perhaps a type of harm as well). Furthermore, the caregivers ought to contemplate, weigh, and balance the relevance of sex in terms of how it may contribute to Donna's well-being and happiness. Could engaging in sex be helpful for her when it comes to her health and well-being (which would be relevant to a principle of beneficence)? If Donna's well-being is of the utmost importance, and if she can be prevented from experiencing undue harm, then perhaps a sexual act could be seen as ethically defensible from the perspective of beneficence and well-being. According to Beauchamp and Childress, undergoing this kind of process of weighing and balancing in light of Donna's individual convictions should eventually lead to an ethically defensible and agreed upon conclusion.

We have some real answers to a few of the above questions and considerations from reports of the Rayhons's case. According to available reports, Donna was in the later stages of dementia, potentially making it difficult for her to truly understand and appreciate the possible consequences of a sexual activity and to make an autonomous decision, even, perhaps, with support.²² She was always happy to see her husband when he arrived at her nursing home and she initiated sexual activities when he was there. There were "no allegation[s] that Mrs. Rayhons resisted or showed signs of abuse"²³ and they had a loving relationship prior to her dementia diagnosis. The details of her pre-dementia sex life were unpublished.

If we think about this situation in light of principles such as autonomy, beneficence, non-maleficence, justice, trust, etc., we might argue that it could be helpful to prioritize Donna's well-being over some of the other principles and norms, especially since she expressed a specific desire to engage in sexual acts with her husband through assent and since they had a loving relationship (potentially reducing the likelihood of experiencing undue harm). Also, since the principle of non-maleficence would be important to consider, it may be important to ensure that she assented prior to *and* during a sexual interaction. So, based on Donna's stage of dementia, her and Henry's relationship prior to and during her dementia diagnosis, her expressed desire to engage in sexual acts through sexual assent, and her lack of passivity or dissent, it could be argued that prioritizing her well-being and balancing this with a principle of non-maleficence would be ethically defensible.

It should be highlighted, however, that according to Beauchamp and Childress, an individual's current convictions ought to be considered when it comes to a process of weighing

²² This is a speculation since Donna Rayhons's capacity to make autonomous choices was not specified in available reports.

²³ Belluck, "Sex, Dementia and a Husband on Trial at Age 78."

and balancing. This means that it is necessary to evaluate cases of sex and dementia in a case-specific *and* time-specific manner. If it eventually seems that Donna may experience more harm than benefit from engaging in sex with her husband, then the principles and potential options may need to be weighed differently.

Weighing and Balancing—the case of the nun:

To take another scenario, suppose a person with dementia was a nun prior to her dementia diagnosis, explicitly expressing a value to maintain a life of chastity. Now, suppose that after being diagnosed with dementia this person expresses a desire to engage in sexual acts, attempting to initiate sexual activities with residents in her nursing home. Suppose that she is unable to make autonomous decisions with support and her current acts clearly conflict with her prior autonomous choices and values. In this kind of case, how should we weigh and balance some of the ethical principles and norms?

For this kind of case it may be argued that protecting the nun from experiencing certain dignitary harms, which could result from allowing her to immediately engage in sex, would be the most important factor to consider given the significance of her prior values. However, if she is in a more advanced stage of dementia, then it would also be important to consider her well-being and a principle of non-maleficence. Would it be helpful to the nun's well-being and happiness for her to engage in sexual acts? Alternatively, given the significance of her pre-dementia identity, could engaging in sex potentially cause significant harm (even if she is unaware of it)? In order to approach this case, perhaps a few questions could be initially considered:

- 1) Does this person know/remember that she was a nun? Does she say anything about being a nun during moments of lucidity?
- 2) Does this person *only* want to engage in sexual acts? Does she potentially desire something that could be offered without any ethical qualms (e.g. a friend, non-sexual contact with another person)?
- 3) What are the potential benefits and risks of allowing her to engage in sexual acts?

A person's prior autonomous decisions may be important to consider under all circumstances (specifically if they are unable to make autonomous choices in a present context), but perhaps they are especially pertinent when the decisions are very specific and maintained over a long period of time. A nun's choice to maintain a life of chastity would fit under this category. In order to honour the nun's prior autonomous choices, perhaps other non-sexual practices could be initially encouraged (e.g. hand-holding, etc.) as a matter of trying to weigh and balance principles of non-maleficence and that of beneficence (trying to help satisfy her needs and desires). If, however, this person only wants to engage in sexual acts and becomes distressed when she is encouraged to partake in other activities, then perhaps her happiness and well-being should be given more weight above her (precedent) autonomy even if this leads to unwanted harm based on prior preferences—perhaps it would be seen as unfair to prevent her from engaging in sexual acts. Although a principle of beneficence and that of well-being are important to consider, the significant, consistent, and specific values and decisions of a former nun would need to be taken seriously, even if she does not remember them.

If this person remembers that she was a nun and/or if during moments of lucidity she talks about being a nun in a negative way, however, then perhaps this ought to be considered as part of the weighing and balancing process as well. Is it possible that becoming a nun was originally *not*

an autonomous choice? Did she have a negative experience after becoming a nun? Alternatively, if this person talks about her past experiences in a positive way and if it seems that it would be harmful for her to engage in sex, then perhaps her prior autonomous decisions should be weighed significantly as a matter of respecting the principle of (precedent) autonomy and dignity.

Weighing and Balancing—LGBTQ case:

Moving away from the previous two cases, I will now consider scenarios involving LGBTQ people, such as the fourth case discussed in Chapter Two. In this case, a nursing assistant discovered two men with dementia having sex, and the men were immediately separated and chastised. It is likely that the men in this scenario would have experienced significant stigmatization in society, especially in the late 1990s which is when this case occurred.

In general, LGBTQ people are more likely to be stigmatized and to encounter potentially harmful biases from others; this potential for harm ought to be considered when it comes to thinking about sex and LGBTQ people with dementia—weighing and balancing a principle of non-maleficence may be especially important to consider. It may be the case that preventing some LGBTQ individuals from engaging in sexual acts could create significant harm and be detrimental to their happiness and well-being because of their prior oppressive experiences. So, in these cases we may want to ensure that their freedom for sexual expression is prioritized by weighing principles of justice, beneficence, and well-being significantly. However, LGBTQ people who also identify as members of other oppressed groups may require further protection from undue harm. For instance, a lesbian cisgender woman with dementia may experience more and/or different types of harm in comparison to a gay cisgender man with dementia. As

discussed in Chapter One, women (both with and without dementia) are more likely to be submissive in sex and to submit to others' sexual requests irrespective of their own preferences. Depending on the circumstances, it may be the case that a lesbian woman with dementia would be more likely to experience undue harm by submitting to unwanted sex in comparison to a gay cisgender male. These individual experiences will need to be considered in a process of weighing and balancing.

The principle of autonomy is always important to weigh and balance for cases of sex and dementia, and in most cases, autonomous decisions will probably be respected. If an LGBTQ person is only able to make autonomous decisions with support, however, then it may be important to proceed with some caution—a support network may need to consider whether they have any known biases/conflicting personal preferences that could influence their ability to enable autonomous decision-making in the right way. If the person with dementia is unable to make autonomous choices and/or if an adequate support network does not exist, then it may be the case that sexual acts could still be defensible from the perspective of beneficence, well-being, dignity, and justice. These principles may override the principle of autonomy when it comes to LGBTQ people in order to ensure that their past experiences of injustice and discrimination do not recur; prioritizing a person's happiness and well-being may be the most important factor to consider. Ultimately, the principles would need to be weighed and balanced based on individuals' present convictions, alongside any relevant past experiences to every case.

4- Conclusions

In this chapter, I initially described and built on some of the positive and negative considerations of each of the frameworks introduced in this dissertation. There are many factors

to consider for each of the frameworks, and since every case of sex and dementia will be different, each case will need to be approached differently. Instead of arguing in support of one framework for every context, I suggested that it would be necessary to approach cases of sex and dementia on case-by-case basis.

In order to evaluate the many principles and norms that are relevant to the frameworks and to consider them on a case-by-case basis, I introduced Beauchamp and Childress's theory of principlism. Principlism is a theory that considers four primary principles as especially important to bioethics. Beauchamp and Childress suggest that a process of weighing and balancing can be helpful for thinking through ethical dilemmas. Upon encountering an ethical dilemma, they say that the principles and norms should be weighed and balanced in light of an individual's convictions and any other aspects that are relevant to a particular case. The principles and norms that will need to be weighed and balanced for cases of sex and dementia expand beyond Beauchamp and Childress's four principles.

After introducing Beauchamp and Childress's method of weighing and balancing, I considered different types of scenarios involving sex and dementia and contemplated some of the principles and norms that may be relevant to a process of weighing and balancing. The first scenario was the case of Henry Rayhons, the second scenario involved a nun with dementia, and the third scenario considered cases involving LGBTQ persons. The purpose of presenting these scenarios was to show how a process of weighing and balancing may work in order to achieve some kind of ethically defensible decision. Also, these examples showed that every case will be treated differently. Approaching cases of sex and dementia will differ depending on the stage of a dementia diagnosis, the presence of support networks, additional intersectional challenges, etc., and it is impossible to determine exactly how every kind of case would be managed in real-life.

Ultimately, this chapter showed that there are many complex factors to consider when it comes to cases of sex and dementia, making it impossible to solely endorse one framework. A case-by-case process of weighing and balancing different principles, norms, and factors that are motivated by the frameworks will help to determine the most ethically justifiable approach.

Conclusion

This dissertation considered sex, consent, and people with dementia. The number of people diagnosed with dementia is expected to increase to almost seventy-five million by the year 2030 and some of these people will want to engage in sexual acts; this has created significant discomfort and uncertainty, especially for people working in nursing home and long-term care settings. The primary cause for discomfort is that many people with dementia are unable to consent to sex in typical ways, and consent is legally and morally significant in Western liberal contexts. In addition to consent, there are some other factors that also contribute to society's discomfort, such as: (1) ageist conceptions that fail to consider older people as sexual (and people older than sixty-five make up most of the dementia population); (2) ideas that people with cognitive impairments are non-sexual; and (3) moralized and taboo perceptions about sex and who ought to engage in sex in general. The intersection of these stereotypes *and* a dementia diagnosis almost certainly contributes to our society's anxiety about sex and dementia, which may lead some to conclude that people with dementia should not engage in sex.

Cases of sex and people with dementia have gained an increasing amount of attention in recent years, and the need for our society to start thinking about how to manage these cases is salient. Should people with dementia be prevented from engaging in sex if they cannot consent in traditional ways? Should we reconceptualize what consent means for the dementia population? The purpose of this dissertation was to consider this complex topic and to explore some potential ways to approach these questions.

In Chapter One, I highlighted some of the primary challenges of sex and the dementia population. I provided a historical overview of sexual consent to show why it is legally and morally important. I also presented different models of sexual consent and emphasized that many people with dementia would be unable to consent accordingly. I introduced intersectional

challenges since it may be the case that some people who identify as members of certain groups may experience particular challenges when it comes to sex and consent. For instance, some LGBTQ people may be socialized to engage in certain types of sex/sexual roles and/or to be passive when it comes to sex, and an LGBTQ person with dementia may experience similar and/or exacerbated challenges.

I presented different cases of sex and dementia in the subsequent chapter. These cases strengthened some of the claims that I made in Chapter One by showing that people with dementia do have sex and that they may be unable to consent to sex in traditional ways. Furthermore, some of the cases highlighted relevant intersectional challenges, including women and LGBTQ people with dementia. Each of these cases caused distress for the parties involved, sometimes resulting in legal and life-changing consequences. In response to these kinds of cases, I argued that enabling sexual expression for people with dementia while at the same time protecting them from undue harm is important. Reconceptualizing what is meant by consent for people with dementia, how consent can be obtained, and/or evaluating the importance of consent (vs. assent, etc.) ought to be considered.

Chapters Three, Four, and Five introduced three frameworks that could be used to approach cases of sex and dementia; the first two considered different ways to conceptualize autonomous consent for people with dementia and the final framework prioritized well-being as a factor that may override autonomy and consent. I presented one framework in each chapter and considered some potential positive and negative considerations of each. The first framework was that of relational autonomy and supported decision-making. This framework considered the possibility of enabling people with dementia to make autonomous sexual decisions with support. The second framework introduced an approach of advance sexual consent, which focused on a

person's prior sexual decisions in relation to their interests after a dementia diagnosis. The third framework considered the potential benefits of prioritizing a person's well-being through desire, pleasure, and happiness.

In my final chapter, I argued that none of the three frameworks would necessarily be preferable in every context because of the various factors that are relevant to cases of sex and dementia — different cases will need to be managed differently. I suggested that an integrated framework would be more helpful in order to consider the different principles and norms, as well as any other factors that are important to consider for particular cases.

In order to approach cases of sex and dementia through an integrated approach, I introduced Beauchamp and Childress's theory of principlism and their approach to bioethical dilemmas. Principlism considers four principles as primarily relevant to bioethics: autonomy, beneficence, non-maleficence, and justice. There are other principles and norms that may also be relevant to cases of sex and dementia, such as dignity, well-being, and precedent autonomy. Beauchamp and Childress realize that in many bioethics cases, the principles and norms may conflict with one another. So, in order to approach ethical dilemmas, they introduce a process of weighing and balancing. This process considers how different norms and principles should be weighed in comparison to other norms/principles based on individual convictions. Weighing and balancing takes many factors into account in order to determine what action(s) is most ethically defensible. According to this framework, sexual acts would not be immediately barred based on a person's inability to consent. Rather, the ethical permissibility of a sexual act would be determined based on all things considered.

The considerations and frameworks presented in this thesis are an important step forward in determining how cases of sex and dementia ought to be approached. This dissertation was

based on the foundational assumption that it may ethically illicit to immediately prohibit people with dementia from engaging in sexual acts if they cannot consent in typical ways, specifically, in the ways described in Chapter One. Based on this starting point, it is unlikely that this dissertation will be helpful for anyone who considers our traditional forms of consent to be appropriate for all populations and/or is uninterested in considering these complex ethical issues. Further research to explore may be to consider how an integrated approach would work in practice, while taking into account questions of privacy and confidentiality. If most citizens, healthcare providers, ethicists, legal scholars, etc. agree that our current approaches to sexual consent do not adequately consider some of the specific factors that are relevant to our aging population, then perhaps this dissertation can serve as a starting point for developing a more nuanced approach. At the very least, I hope that I have shown that our traditional models of consent may need to be reconceptualized for people with dementia and that this topic requires further exploration to approach these cases in practice.

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